
THE UNIVERSITY
*of* EDINBURGH

# New care home admission following acute hospitalisation

## A mixed methods approach


Jennifer Kirsty Burton

Doctor of Philosophy
The University of Edinburgh
2018

*For May and Tom, Sheila and Liston, Carol and Alex, and all the other older people I have had the privilege to be inspired-by*

"No number without stories and no stories without numbers"

Professor Claire Goodman, Professor of Healthcare Research, University of Hertfordshire
Care Homes Conference, Salford 26th April 2017

# DECLARATION

The work presented in this thesis has been composed by myself and the work is my own except where acknowledgment is made by reference. The work in this thesis has not been submitted for any other degree or professional qualification.

March 2018

# CONTENTS

# APPENDICES

# LIST OF TABLES

# LIST OF FIGURES

# ACKNOWLEDGEMENTS

I am very grateful to all of my supervisors, who have each made unique contributions to my work and development. With thanks to Susan Shenkin for her endless patience, kindness and encouragement; to Alasdair MacLullich for inspiration and support in exploring a novel area; to Emma Reynish for her inclusive approach and facilitating opportunities for collaboration; and to John Starr for offering balance, insight and general wisdom.

**Chapter Three**: I thank Katherine Walesby, Eilidh Ferguson and Susan Shenkin for their help with in screening and data extraction. Thanks to Azucena Garcia Garrido, Lisa-Marie Rutter and Zoë Tieges for translation of abstracts and full texts. Thanks to Sheila Fisken for advice on designing the search and to Carolyn Armstrong and Lorna Hamilton for papers from their 2014 search to inform search strategy design. Thanks also to Terry Quinn for advice on the meta-analysis and use of Comprehensive Meta-Analysis software.

**Chapter Four**: I would like to thank Yves Rolland and Adam Gordon for support in dissemination of the survey and to all those who took time to submit a response. Thanks are also due to Terry Quinn for raising awareness of search filters as a potential methodology to include in this thesis.

**Chapter Five**: I thank Azucena Garcia Garrido for collection of the data and Gemma Logan, Juliet MacArthur, Alasdair MacLullich, Sarah Rhynas and Susan Shenkin for design of the data extraction form.

**Chapter Six**: I would like to thank the patients, their families and members of the multidisciplinary team who gave up their time to participate in the study. I am very grateful to Gemma Logan, Juliet MacArthur and Sarah Rhynas for the opportunity to collaborate in the One Chance study, for their support and friendship. Particular thanks to Sarah Rhynas for providing critical review of my draft chapter and analysis.

**Chapter Eight**: I thank Simona Hapca for linking the data and for her time spent explaining and sharing SAS syntax. I would also like to thank Mike Ghattas, Christopher Hall and James Galloway from the Health Informatics Centre in Dundee for data provision. Particular thanks also to Bruce Guthrie for involving me in the wider project to improve care home identification and acting as second reviewer on all address data.

**Chapter Nine**: I am eternally grateful to Ellen Lynch for her support in establishing the project, for arranging access to standalone data and facilitating my Knowledge Exchange Placement in the Health and Social Care Analysis Division of the Scottish Government. Thanks to Dionysis Vragkos and Fiona Campbell at eDRIS and Rachel Porteous of the ISD Care Homes Team for their assistance in accessing data. I must also thank Ingrid Gilray and Al Scougal of the Care Inspectorate for their help in understanding the data.

I am grateful to those who have shared their time and wisdom during the course of this thesis, particularly: Feifei Bu, Anne Canny, Claire Copeland, Daniel Davis, Claire Goodman, Victoria Haunton, David Henderson, Thomas Jackson, Elizabeth Lemmon, Marilyn Kendall, Louise McCabe, David Oliver, Julia Prague, Justin Praino, Sarah Richardson, Julie Rintoul, Jane Robertson, Tom Russ, Alasdair Rutherford, Lucy Stirland and Elizabeth Stirling. I am particularly grateful to Charlotte Clarke and Gillian Mead for their guidance offered while acting as my internal reviewers.

I am very grateful for the administrative support and kindness of Maureen Harding, Sharon Moncrieff, Denise Munro, Beverly Roberts, Elaine Smith and Steph West. I have benefited from supportive colleagues in Geriatric Medicine, particularly Amanda Barugh and Zoë Tieges. I have been inspired by Katherine Walesby, as a friend and colleague and constant source of encouragement and support.

My Clinical Research Fellowship was fully funded by the Alzheimer Scotland Dementia Research Centre and the University of Edinburgh Centre for Cognitive Ageing and Cognitive Epidemiology, part of the cross council Lifelong Health and Wellbeing Initiative (MR/L501530/1). Funding from the Biotechnology and Biological Sciences Research Council (BBSRC) and Medical Research Council (MRC) is gratefully acknowledged.

Additional funding was awarded to support the work described in Chapters Five, Six and Nine from: the Alex and Elizabeth Gibson Trust (*Scottish Charity Number: SC043311*; PI: J MacArthur); the Edinburgh and Lothians Health Foundation (*Scottish Charity Number: SC007342*; PI: G Logan*)* and the Scottish Government Analytical Leadership Group through the Scottish Informatics and Linkage Collaboration (PI: J Harrison), respectively.

Final thanks are reserved for my unfalteringly supportive family, without whom, this would not have been possible. To my mother Fiona for continuous editorial and emotional support and to my father Robert for encouraging me to challenge my thinking. Lastly to my husband Joel, for moving to enable us to continue my research journey side-by-side, for believing in me and supporting me to be better than I am.

# PUBLICATIONS

## Papers arising directly from work presented in this thesis

1. **Harrison JK**, Garrido AG, Rhynas SJ, Logan G, MacLullich AMJ, MacArthur J, Shenkin SD. New institutionalisation following acute hospital admission: a retrospective cohort study. *Age and Ageing*. 2017;46(2):238-44. PMID: 27744305
2. **Harrison JK**, Reid J, Quinn TJ, Shenkin SD. Using quality assessment tools to critically appraise ageing research: a guide for clinicians. *Age and Ageing*. 2017;46(3):359-65. PMID: 27932357.
3. **Harrison JK**, Walesby KE, Hamilton L, Armstrong C, Starr JM, Reynish EL, MacLullich AMJ, Quinn TJ, Shenkin SD. Predicting discharge to care home following acute hospitalisation: a systematic review & meta-analysis. *Age and Ageing*. 2017; 46(4):547-558. PMID: 28444124.
4. **Harrison JK**, MacArthur J, Garrido AG, Logan G, Rhynas SJ, MacLullich AMJ, Shenkin SD. Decisions affecting discharge from hospitals to care homes. *Nursing Times*. [Invited Discussion Paper]. 2017;113(6):29-32.
5. **Burton JK**, Quinn TJ, Gordon AL, MacLullich AMJ, Reynish EL, Shenkin SD. Identifying published studies of care home research: an international survey of researchers. *Journal of Nursing Home Research*. 2017; 3:99-102.
6. **Burton JK**, Ferguson E, Barugh AJ, Walesby KE, MacLullich AMJ, Shenkin SD, Quinn TJ. Predicting discharge to institutional long-term care after stroke: a systematic review & meta-analysis. *Journal of the American Geriatrics Society*. 2018;66(1):161-169. Available online. PMID: 28991368.

## Other papers on care home research published during the course of this thesis

1. **Harrison JK***/McKay IK*, Grant P, Hannah J, Quinn TJ. Appropriateness of unscheduled hospital admissions from care-homes. *Clinical Medicine*. 2016;16(2):103-8. PMID: 27037376. ** Joint first authors*
2. Siddiqi N, Cheater F, Collinson M, Farrin A, Forster A, George D, Godfrey M, Graham E, **Harrison J**, Heaven A, Heudtlass P, Hulme C, Meads D, North C, Sturrock A, Young J. The PiTSTOP study: a feasibility cluster randomized trial of delirium prevention in care homes for older people. *Age and Ageing*. 2016;45(5):652-61. PMID: 27207749.
3. Teale E, Young J, Siddiqi N, Munyombwe T, **Harrison J**, Schuurmanns M. Study protocol: Investigation of the Delirium Observation Screening Scale (DOSS) for the routine detection of delirium in the care home setting: a prospective cohort study. *BMJ Open*. 2016;6(6):e009615. PMID: 27324706.

4. Hockley J, **Harrison JK,** Watson J, Randall M, Murray S**.** Fixing the broken image of care homes: could a 'care home innovation centre' be the answer. *Age and Ageing*. 2017;46(2):175-8. PMID: 27609210
5. **Burton JK**, Guthrie B. Identifying who lives in a care home – a challenge to be conquered. *Age and Ageing*. [Editorial]. 2018; 47(3):322-323. PMID: 29346469.
6. Rhynas SJ, Garrido AG, **Burton JK**, Logan G, MacArthur J. New care home admission following hospitalisation: how do older people, families and professionals make decisions about discharge destination? A case-study narrative analysis. *International Journal of Older People Nursing*. 2018. Available online 24/03/2018. PMID: 29573561.
7. **Burton JK**, Papworth R, Haig C, McCowan C, Ford I, Stott DJ, Quinn TJ. Statin Use is Not Association with Future Long-Term Care Admission: Extended Follow-Up of Two Randomised Controlled Trials. *Drugs & Aging*. 2018. Available online 19/6/2018. PMID:29916140.

**Other papers published during the course of this thesis**

1. Siddiqi N, **Harrison JK**, Clegg A, Teale EA, Young J, Taylor J, Simpkins SA. Interventions for preventing delirium in hospitalised non-ICU patients. *Cochrane Database of Systematic Reviews*. 2016. Issue 3 CD005563. PMID: 26967259
2. Maile E, **Harrison JK**, Chikura G, Russ K, Conroy SP. Ethical Issues for Older People in the Emergency Department. *European Geriatric Medicine*. 2016;7(4):372-8.
3. Conroy SP, **Harrison JK**, Van der Wardt V, Welsh T, Logan P, Gladman JR. Ambulatory blood pressure monitoring in older people with dementia: a systematic review of tolerability. *Age and Ageing*. 2016;45(4):456-62. PMID: 27055877.
4. Jongstra S, **Harrison JK**, Quinn TJ, Richard E. Antihypertensive withdrawal for the prevention of cognitive decline. *Cochrane Database of Systematic Reviews*. 2016. Issue 11. PMID: 27802359
5. **Harrison JK**, Van der Wardt V, Conroy SP, Stott DJ, Dening T, Gordon A, Logan P, Welsh T, Taggar J, Harwood R, Gladman JRF. New horizons: The management of hypertension in people with dementia. *Age and Ageing*. 2016;45(6):740-6. PMID: 27836926.
6. **Harrison JK**, Noel-Storr AH, Delemeyre N, Reynish EL, Quinn TJ. Outcomes measures in a decade of dementia and mild cognitive impairment trials. *Alzheimer's Research and Therapy*. 2016;8:48. PMID: 27866472.

7. **Harrison JK**, Stott DJ, McShane R, Noel-Storr AH, Swann-Price RS, Quinn TJ. Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) for the early diagnosis of dementia across a variety of healthcare settings. *Cochrane Database of Systematic Reviews*. 2016. Issue 11. PMID: 27869298.
8. Van der Wardt V, **Harrison JK**, Welsh T, Conroy S, Gladman J. Withdrawal of antihypertensive medication: a systematic review. *Journal of Hypertension*. 2017;35(9):1742-9. PMID 28486271.
9. Shenkin SD, **Harrison JK**, Wilkinson T, Dodds RM, Ioannidis JPA. Systematic reviews: guidance relevant for studies of older people. *Age and Ageing.* 2017;46(5):722-8. PMID 28655142.
10. Walesby KE, **Harrison JK**, Russ TC. What big data could achieve in Scotland. *Journal of Royal College of Physicians of Edinburgh*. 2017;47(2):114-9. PMID 28675178.
11. Todd A, Blackley S, **Burton JK**, Stott DJ, Ely EW, Tieges Z, MacLullich AMJ, Shenkin SD. Reduced level of arousal and increased mortality in adult acute medical admissions: a systematic review and meta-analysis. *BMC Geriatrics*. 2017;17(1):283. PMID 29216846
12. Van der Wardt V, **Burton JK**, Conroy S, Welsh T, Logan P, Taggar J, Tanajewski L, Gladman J. Withdrawal of antihypertensive therapy in people with dementia: feasibility study. *Pilot and Feasibility Studies*. 2018. 4:29. PMID: 29340166.
13. Ward E, Gillies J, Armstrong D, Grant L, Elder A, **Burton J**, Ryan C, Quinn C. Cultivating compassionate care: why does it matter and what can we do to promote it? *Journal of the Royal College of Physicians of Edinburgh*. 2018;48(1):71-7. PMID: 29741533.

# ABSTRACT

Care home admission following acute hospitalisation is a lived reality across Scotland, experienced by over 8,000 people annually. The aim of this thesis was to develop an understanding of new care home admission following acute hospitalisation. Methods and findings from the mixed-methods approach are presented in three parts.

**Part One: Identifying relevant research** – includes a review of quality assessment tools for systematic reviewing; a systematic review and meta-analysis of quantitative data from observational studies of predictors of care home admission from hospital; and a methodological chapter on developing a search filter to improve accessibility of existing research findings supported by the findings of an international survey of care home researchers.

The systematic review identified 53 relevant studies from 16 countries comprising a total population of 1,457,881 participants. Quantitative synthesis of the results from 11 of the studies found that increased age (OR 1.02 per year increase; 95%CI 1.00-1.04), female sex (OR 1.41; 95%CI 1.03-1.92), dementia & cognitive impairment (OR 2.14; 95%CI 1.24-3.70) and functional dependency (OR 2.06; 95%CI 1.58-2.69) were all associated with an increased risk of care home admission after hospitalisation. Despite international variation in service provision, only two studies described the model of care provided in the care home setting.

The survey identified that there is a lack of shared terminology in the published literature to describe settings for adults who are unable to live independently in their own homes and require care in a long-term institutional setting. A search filter to identify relevant research could help to overcome differences in terminology and improve synthesis of existing research evidence.

**Part Two: Exploring current clinical practice** – reports the findings of a retrospective cohort study of new care home admissions from hospital using case-note review methodology accompanied by findings from inductive thematic analysis of a single dataset from a qualitative case study design exploring the experiences of a patient, their family, and practitioners (n=5).

The cohort study (n=100) found a heterogeneous picture with long hospital admissions (range 14-231 days), frequent transfers of care (31% experienced three or more transfers), varied levels of documented assessment and a lack of documented patient involvement in the decision-making processes. The qualitative interviews allowed the patient voice to emerge, alongside the professional and family narrative which dominated case-note documentation. Inductive thematic analysis identified nine major themes exploring how decisions are made to discharge individuals directly into a care home from the acute hospital setting: biography & personality; professional role; family role; limitations in local model of care; ownership of decision; risk; realising preferences; uncertainty of care home admission process; and psychological impact of in-hospital care.

**Part Three: Harnessing routinely-collected data** – includes the challenges of identifying care home residency at admission and discharge from hospital, presenting analysis of the accuracy of Scottish Morbidity Record 1 (SMR01) coding in NHS Fife and the Community Health Index (CHI) Institution Flag in NHS Fife and NHS Tayside. This is followed by a descriptive analysis of the

Scottish Care Home Census (2013-16) as a novel social care data source to explore care home admissions from hospital and the methodology for a data linkage study using these data.

Identifying care home residents in routine data sources is challenging. In 18,720 admissions to NHS Fife, SMR01 coding had a sensitivity of 86.0% and positive predictive value of 85.8% in identifying care home residents on admission. At discharge the sensitivity was 87.0% and positive predictive value was 84.5%. From a sample of 10,000 records, the CHI Institution Flag had a sensitivity of 58.6% in NHS Fife and 89.3% in NHS Tayside, with positive predictive values of 99.7% and 97.7% respectively.

From 2013-16, of 21,368 admissions to care homes in Scotland, 56.7% were admitted from hospital. There was significant regional variation in rates of care home admission from hospital (35.9-64.7%) and proportion of Local Authority funded places provided to admissions from hospital (34.4-73.9%). Those admitted from hospital appeared to be more dependent and sicker than those admitted from home.

This thesis has established a series of challenges in how care homes and their residents are identified. It has questioned the adequacy of the evidence to guide practitioners and sought to raise the profile of this vulnerable and complex population and how best to support them in making decisions regarding admission from the acute hospital. It has progressed our understanding of this under-explored area and proposes a programme of future mixed-methods research involving patients, families, practitioners and policy-makers.

# LAY SUMMARY

Being admitted to a care home is an important and life-changing decision for any individual and their family. However, it can be an important and necessary way to provide care and support when a person's needs cannot be met in their own home. Every year, there are around 13,000 admissions to over 1,200 Scottish care homes, of whom ~8,000 are admitted from hospital. UK health policy documents argue that we should avoid care home admission from the acute hospital. Despite this, little research has been done to guide doctors, nurses, social workers and individuals and their families in this area.

This thesis has explored a pragmatic topic by taking a range of approaches. These included: reviewing published research; surveying practitioners; studying individuals using their hospital case notes; interviewing patients, families and staff and; using data collected routinely by the NHS and care homes.

Reviewing published research found 53 studies in 16 countries which considered predictors of care home admission from hospital. The main factors linked to this were increasing age, being female, having dementia and being limited in daily activities. Other factors, which may be important to older people and their families, were not considered. Care-home services are organised differently across the world and most studies did not describe the care provided. The survey found that many different terms (including 'Nursing Home' and 'Long-term Care) are used to describe care homes, making it difficult for researchers to find relevant studies.

The clinical case-note review found differences among the in-hospital experiences and assessments of those discharged to a care home from hospital. The patient's own views were seldom recorded in their hospital notes. In the interviews, however, the opinions of the patients, their families and the staff caring for them were heard, offering insights into how the decisions are made and how best to support those involved.

Identifying who lives in a care home using data is challenging. Comparing different methods, including postcode matching and hospital coding, found these do not always agree. It is important that researchers and those using data to compare hospitals, are aware of the limitations of each method. The Scottish Care Home Census (2013-2016) includes 21,368 admissions to care homes: 56.7% from hospital. These data showed variations in the care needs, funding patterns and the number and proportion of individuals moving from hospital.

The work described in this thesis has provided the first description and quantification of the challenges of identifying care home residents using routinely-collected health & social care data in Scotland. It has also allowed the first national description of those admitted to care homes in Scotland – from hospital and from home. It has enabled the views of patients, their families and those involved in their hospital care to be expressed and will help to inform guidance to support practice.

Future research should involve exploring and improving the available data and using them to direct more specific work with all those involved in decisions about long-term care. The ultimate aim is to use data and research to inform health and care policy and practice in Scotland, to support older people needing long-term care.

# ABBREVIATIONS

95% CI: 95% Confidence Interval

ACCORD: Academic and Clinical Central Office for Research and Development

ACE-III: Addenbrooke's Cognitive Examination – III

ADL: Activities of Daily Living

ADRC: Administrative Data Research Centre

AMT: Abbreviated Mental Test Score

AMU: Acute Medical Unit

AwI: Adults with Incapacity

BLISS: Beaumont Lifestyle Inventory of Social Support

BOOMER: Balance Outcome Measure for Elder Rehabilitation

BPSD: Behavioural and Psychological Symptoms of Dementia

BRASS: Blaylock Risk Assessment Screening Score

CADTH CAI: Canadian Agency for Drugs and Technologies in Health Critical Appraisal Instrument

CAM: Confusion Assessment Method

CASP: Critical Appraisal Skills Programme

CFAS: Cognitive Function and Ageing Studies

CGA: Comprehensive Geriatric Assessment

CH: Care Home

CHI: Community Health Index

COMET: Core Outcome Measures in Effectiveness Trials

COREQ: COnsolidated criteria for REporting Qualitative research

CSO: Chief Scientist Office

DNACPR: Do Not Attempt Cardio-Pulmonary Resuscitation

DTA: Diagnostic Test Accuracy

ED: Emergency Department

eDRIS: electronic Data Research and Innovation Service

EPOC: Effective Practice and Organisation of Care

EQUATOR: Enhancing QUAlity and Transparency Of health Research

EUGMS: European Geriatric Medical Society

FIM: Functional Independence Measure

GARN: Global Ageing Research Network

GEMS: Gait, Eyesight, Mental state, Sedation

GRADE: Grading of Recommendations Assessment Development and Evaluation

HBCCC: Hospital-Based Complex Clinical Care

HIC: Health Informatics Centre

HSCDIIP: Health and Social Care Data Integration and Intelligence Project

HR: Hazard Ratio

IAGG: International Association of Geriatrics and Gerontology

ICD: International Classification of Diseases

ICHOM: International Consortium for Health Outcomes Measurement

Inter-RAI: Inter-Resident Assessment Instrument

IoRN: Index of Relative Need

ISD: Information Services Division

ISSG: Information Specialists' Sub-Group

IQR: Inter-quartile range

LA: Local Authority

LTC: Long Term Care

MDS: Minimum Data Set

MDT: Multi-Disciplinary Team

MeSH: Medical Subject Headings

MMSE: Mini Mental State Examination

NHRWG: Nursing Home Research International Working Group

NHS NSS: NHS National Services Scotland

NICE: National Institute for Health and Care Excellence

NIHSS: National Institute for Health Stroke Scale

NLP: Natural Language Processing

NNR: Number Needed to Read

NOS: Newcastle-Ottawa Quality Assessment Scale

NR: Not Reported

NRS: National Records of Scotland

OPRAA: Older Person's Routine Acute Assessment

OR: Odds Ratio

PAF: Postcode Address File

PBPP: Public Benefit and Privacy Panel

PIS: Prescribing Information System

PoA: Power of Attorney

PPI: Patient Public Involvement

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PSD: Practitioner Services Division

R&D: Research and Development

RCTs: Randomised Controlled Trials

REC: Research Ethics Committee

RIE: Royal Infirmary of Edinburgh

RIGMA: Risk Index for Geriatric Acute Medical Admissions

RN: Research Nurse

RoBANS: Risk of Bias Assessment tool for Non-Randomised Studies

ROBINS-I: Risk of Bias In Non-randomised Studies – of Interventions

RR: Risk Ratio

SCHC: Scottish Care Home Census

SD: Standard Deviation

SHeS: Scottish Health Survey

SIG: Special Interest Group

SIGN: Scottish Intercollegiate Guidelines Network

SILC: Scottish Informatics and Linkage Collaboration

SMR: Scottish Morbidity Record

SLS: Scottish Longitudinal Study

SPARRA: Scottish Patients at Risk of Readmission and Admission

SPIRE: Scottish Primary Care Information Resource

STROBE: Strengthening of the Reporting of Observational Studies in Epidemiology

WGH: Western General Hospital

WOSCOPS: West of Scotland Coronary Prevention Study

# CHAPTER ONE
# Introduction

Between 2 and 5% of the older adult population worldwide receive 24-hour care in an institutional long-term setting such as a nursing home (Ribbe *et al.*, 1997). In Scotland, there are approximately 35,000 long-stay care home residents, 90% of whom are aged ≥65 years, accounting for 3.2% of the older adult Scottish population (Information Services Division Scotland and NHS National Services Scotland, 2016a, National Records of Scotland, 2017b). Each year over 13,000 people are admitted to a care home as long-stay residents, just under half of whom will have been admitted directly from hospital (Information Services Division Scotland and NHS National Services Scotland, 2016b). Despite this being a life-changing lived experience, it has been poorly described in the medical literature and is highly varied in clinical practice. The aim of this thesis is to develop an understanding of new care home admission following acute hospitalisation. To contextualise this, relevant UK social issues and policy initiatives will be presented, with a focus on those most applicable in Scotland, before discussing the interface between acute hospital care and care homes for older adults. Thereafter, the justification for using new care home admission as an outcome measure will be presented. This Chapter will conclude by explaining the rationale for the mixed methods approach and present the thesis aims and objectives.

## 1.1 SOCIAL AND ECONOMIC CONTEXT

### *1.1.1 Progress and consequences*

Perhaps the greatest achievements of human healthcare over the past century have been the significant improvements in care, treatment and outcomes for a spectrum of diseases, resulting in improved survival. Life expectancy at birth in England and Wales has risen sharply, from 51 and 55 years for males and females in 1911, to 79 and 82 in 2011 (Office for National Statistics, 2015). While initial improvements were largely driven by changes in population health to promote survival in younger people, more recently the trend has been driven by interventions to prolong survival in middle-aged and older adults (Office for National Statistics, 2015).

As a consequence, many of the patients using today's NHS are significantly different from those of a generation ago. Increasingly they are likely to have multiple long-term conditions, particularly if they live in more deprived areas (Barnett *et al.*, 2012). Having survived initial acute episodes, individuals are more likely to make subsequent use of emergency care services, contributing to rising demand for existing services (Laudicella *et al.*, 2017). The spectrum of frailty among older people is also more widely recognised, with increasing frailty associated with greater risk of hospitalisation (Clegg *et al.*, 2016). Dementia is a common comorbidity (Donegan *et al.*, 2017), with recognition of the significant impact of delirium on the outcomes and experiences of older people (Bellelli *et al.*, 2015, Eeles *et al.*, 2010).

Those experiencing the effects of physical frailty, comorbidities and cognitive conditions are more likely to require care in their daily lives. Data from the Cognitive Function and Ageing

Studies (CFAS) indicate that older men and women spend 2.4 and 3.0 years respectively with substantial care needs before death, with the majority receiving care at home (Kingston *et al*., 2017). The CFAS findings indicate the need for more investment in care, both formal and informal, to support individuals (Kingston *et al*., 2017). Informal care is pivotal in supporting individuals to live at home, but the costs associated with this are often invisible to society and system planning (Bremer *et al*., 2017). Importantly, while costs of care home placement are significant, the true costs of informal care are rarely incorporated into models of care at home (Wubker *et al*., 2015). UK population modelling anticipates that extensions in life expectancy are also to be accompanied by increased periods of disability, with up to a quarter of life expectancy after 65 years involving disability (Guzman-Castillo *et al*., 2017). These findings provide strong motivation both to develop interventions to prevent, reduce or delay such disability, coupled with investment in systems of care to help those who require additional support, including assistance for informal carers. This is recognised to require global, system-wide reorganisation to focus care to meet the needs of the older population (Araujo de Carvalho *et al*., 2017).

### *1.1.2 Paying for the care which is required*

A particular challenge facing UK society is how to fund health and social services, particularly the extent of state provision. Geriatric medicine can play a significant part in supporting models of health and social care which promote independence, are co-ordinated, integrated, accessible and can meet the needs of the often complex individuals who require support (Philp, 2015). There has been an historic divide in how health and social care are funded, dating back to the origins of the two systems (Glasby, 2012). Most critical observers note that this divide is a flawed concept, which is particularly arbitrary when considering the care needs of complex older people (Glasby and Littlechild, 2004).

There remains broad societal consensus that health care *via* the NHS should be funded by the State, protecting individuals from exposure to costs depending on their health outcomes and experiences (Dilnot, 2017). However, greater debate exists around funding for social care services (Dilnot, 2017). Successive Governments have commissioned reviews into the optimal funding model. Between 1996 and 2013 there were two independent commissions, three consultations and five White and Green papers examining paying for social care (Humphries, 2013). These have been in response to recognition of rising demand, in the context of population ageing and the need to ensure a fair and justifiable system going forwards. Several potential options have been proposed, all of which require systemic changes and greater investment, none has been fully adopted or implemented (Humphries, 2013). The lack of committed, cross-party action illustrates the complexities and timescales of political decision-making in this critical public and social health issue.

Individual perspectives in society vary considerably in this area, which may account for some of the reticence for action. While there is broad acceptance that the State should care for those who cannot take care of themselves, there are emotive arguments around fairness and the models of assets and inheritance which require some who do not perceive they have material wealth to be asked to contribute more (Hanratty *et al*., 2012). Some have argued that the inclusion of assets in assessment for care funding acts as a disincentive, even when this level of care is necessary,

creating additional burden on their carers (McCann *et al*., 2012). It can be argued that whatever one's position on these issues, it is essential that policymakers, health and social care professionals and the public are informed by accurate data, analysis and research to ensure older people can be supported for generations to come.

## 1.2 POLICY CONTEXT

Recent developments in Scottish and English health and social care policy are relevant in understanding the topic of care home admission from hospital. Awareness of this policy landscape is important to ensure any research conducted is sensitive to the direction of national initiatives and that findings can be interpreted appropriately.

### *1.2.1 Vision 2020*

The Scottish Government's 2020 Vision for Health and Care in Scotland places integration and the provision of high-quality, person-centred care at the core of services with the aim that:

> "*… by 2020 everyone is able to live longer healthier lives at home, or in a homely setting*" (Scottish Government, 2011).

The explicit reference to "or in a homely setting" is an important acknowledgement that not all adults can be supported to live in their own homes. Care homes and other forms of institutional care, including Hospital-Based Complex Clinical Care (HBCCC), have a vital role in supporting some of the most vulnerable and complex in society. The Health & Social Care Delivery Plan for 2016 identified inappropriate admissions to care homes are an issue of concern and an outcome which should be avoided (Scottish Government, 2016c). However, there is no definition provided to judge the appropriateness of care home admission and no data are presented on the estimated scale of this issue.

### *1.2.2 Health and social care integration*

Integration has been championed as a means of addressing the needs of a frailer population with long-term conditions by reducing fragmentation, localising decision-making and organising services around individuals (Scottish Government, 2016d). This is reflected in the following definition of integrated care which was developed through work with service users, carers, charities and families. Integrated care, which they considered as "person-centred co-ordinated care" occurred when:

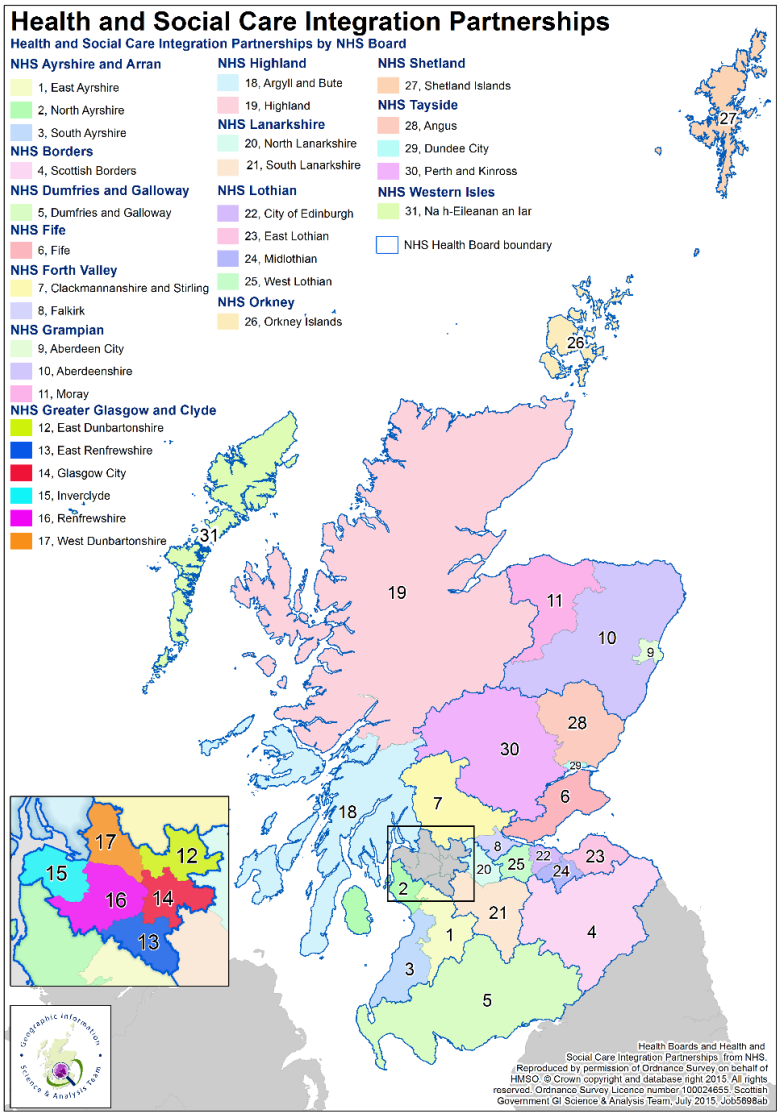
> "*I can plan my care with people who work together to understand me and my carer(s), allow me control and bring together services to achieve the outcomes that are important to me*" (National Voices and NHS England, 2013).

Integration is expected to achieve significant financial savings in the costs of care provision in times of limited resources and financial constraint (National Audit Office, 2017). Analysis by the Nuffield Trust on innovations aiming to achieve what is described as "*a shift in the balance of care*", namely provision of more care out of the acute hospital setting, demonstrates potential

for improvement in patient outcomes and experience, but that cost savings were not guaranteed and some increased costs overall (Imison *et al*., 2017).

Since April 2015 Health and Social Care have been legally integrated in Scotland (Scottish Government, 2015c). In the short term this has led to significant reorganisation in operational structures and the formation of 31 Integration Authorities (**Figure 1.1**) which now control the budget of more than £8 billion, which was previously held by the NHS Health Boards and Local Authorities (Scottish Government, 2017a). The 14 regional Health Board areas may contain several Integration Authorities (**Figure 1.1**). This can mean that two patients in the same hospital have different access to services based on the lower level of geography at which decisions, for example around the availability of social care, are made. Integration of health and social care services by 2020 remains a target across England, but adoption of integrated services has been more locally driven and not always through shared budgets and new organisational structures (National Audit Office, 2017).

**Figure 1.1: Map of the 31 Integration Authorities showing overlap with Health Board Areas** (Ordnance Survey and Scottish Government Geographic Information Science & Analysis Team, 2015)




### *1.2.3 Personal and nursing care*

Since July 2002, Scottish Government policy is to provide access to free personal care to individuals aged over 65 and nursing care without age restriction, to all those who are assessed as requiring it (Scottish Government, 2016b). It is not means tested and is available to those living in the community or in institutional care (Scottish Government, 2015a). Expenditure on free personal and nursing care is growing annually. In 2014-15 £144 million was spent for older people in care homes and £368 million for care at home, compared with £97 million and 189 million respectively in 2005-06 (Scottish Government, 2016a). Assessment is made by the Local Authority and payment is made either directly to the care provider or to the individual to arrange services specific to their needs (Scottish Government, 2015a). The services available are summarised in **Table 1.1**.

**Table 1.1: Care available in Scotland** (Scottish Government, 2015a)

| Care | Definition | Eligibility | Financial |
|---|---|---|---|
| Personal care | Personal hygiene, continence management, food and diet assistance, problems with immobility, counselling and support, 'simple' treatments (assistance with medication/creams and lotions/oxygen) and personal assistance (assistance with dressing, assistance to get up and go to bed and transfers including use of a hoist) | Needs-based assessment<br>>65s eligible | Up to £171/week<br>Equivalent to £8,892/year |
| Nursing care | Care that "involves the knowledge or skills of a qualified nurse – includes activities such as administering injections and managing pressure sores" (COSLA and Scottish Government, 2010) | Needs-based assessment (more stringent criteria)<br>No age restriction | £78/week<br>Equivalent to £4,056/year |
| Additional care services | Housework, laundry, shopping, day care, day centre, lunch clubs, supplying food, pre-prepared meals | Chargeable services, no entitlement for costs to be covered | Cost varies per service, individual is liable for costs |

Free personal care is considered a landmark policy in Scotland, associated with devolution, and it has not been replicated in the other UK nations (Bowes and Bell, 2007). It is consistent with the aims of supporting individuals to receive care at home or in a homely setting described earlier, by removing financial barriers to fundamental care.

In England, social care funding is more complex, depending on assessments by individual Local Authorities, taking account of existing assets (Humphries, 2013). The whole funding system is under significant pressure arising from cuts to Local Authority funding which are changing the eligibility criteria and requiring more individuals to pay for their care (Humphries *et al*., 2016). An additional system to provide support for the costs of care is available where individuals are considered to have continuing healthcare needs. These can be identified using a multidisciplinary decision support tool which then prompts detailed assessment by social services (Department of Health, 2012). In Scotland, if healthcare needs are significant, individuals can be assessed for HBCCC, discussed further in Section 1.6.

### *1.2.4 Transitions from hospital care*

In December 2015, the National Institute for Health and Care Excellence (NICE) published guidance on transition between inpatient hospital settings and community or care home settings for adults with social care needs (National Institute for Health and Care Excellence, 2015a). Much of this affirmed important aspects of the inpatient care for older people, including the formation of a hospital-based Multi-Disciplinary Team (MDT), based around their individual needs and encouragement to follow usual daily routines while inpatients (National Institute for Health and Care Excellence, 2015a). However, one key recommendation was to:

> "*1.5.11 Ensure that people do not have to make decisions about long-term residential or nursing care while they are in a crisis*" (National Institute for Health and Care Excellence, 2015a).

This recommendation is based on good quality evidence (National Institute for Health and Care Excellence, 2015b) derived from a large qualitative study involving interviews and focus groups with a total of 99 health and social care practitioners (Taylor and Donnelly, 2006). This work found that staff were more likely to recommend care home admission when individuals were in a crisis, often in the form of an acute hospital admission (Taylor and Donnelly, 2006). The crisis situation prompted staff to make the recommendation, which they described would usually be based on more objective measures (Taylor and Donnelly, 2006). It was also noted that the pressures of time reduced the choices available to the individual and opportunities to make other care arrangements (Taylor and Donnelly, 2006).

### *1.2.5 Avoidance of care home admission from the acute hospital*

Policy documents from both Scotland and England state that care home admission from the acute hospital setting should be avoided (Audit Scotland, 2014, NHS England, 2014). This is motivated by the view that long-term care admission should only happen when all other options have been exhausted, including ensuring that older people have access to treatment, rehabilitation and support (Oliver *et al*., 2014, Hoare, 2004).

It is reported that there is six-fold variation in the rates of long-term care admission from the acute hospital across England (Oliver *et al*., 2014). The source of these data is the Audit Commission, which since 2015 has been replaced by other organisations, making the original report difficult to access[1]. The six-fold statistic is based on the percentage of people aged ≥65 years who are admitted to hospital from home and discharged to residential or nursing care (Audit Commission, 2011). The data are reported as a percentage range in four categories, each including data from 36 to 39 regions of England, based on Hospital Episode Statistics data from 2009/10 (Audit Commission, 2011). The ranges are 0.14 to 0.75%; 0.75 to 1.14%; 1.14 to 1.61% and 1.61 to 4.61% (Audit Commission, 2011).

In the same year, however, permanent admissions to long-term residential and nursing care across England & Wales varied eight-fold, from 15 to 116 per 10,000 adults aged *≥65* years (*Total population aged ≥65 years 10,508,634 people (Office for National Statistics, 2017)*), based on the Adult Social Care Combined Activity Return data (Audit Commission, 2011). No comparable Scottish data have been published.

In 2015-16 the rate of permanent admissions of those aged ≥65 to residential and nursing care in England was 62.8 per 10,000, lower than the target of 65.9 (National Audit Office, 2017). The rationale for this specific target is not presented in the National Audit Office report. It is interesting to note that the figure is based only on permanent placements which receive Local Authority funding (NHS Choices, 2014). The availability of Local Authority funding for care home placement varies six-fold between Local Authorities and the numbers receiving support across the country are falling (Humphries *et al*., 2016).

[1] *Thanks to Professor David Oliver for assistance in identifying the original source for these data*

To evaluate health and social care integration in Scotland, 23 core indicator measures have been developed, 13 of which will be based on routinely-collected data (Scottish Government, 2015c). Of particular significance to this thesis is:

> "*21. Percentage of people admitted from home to hospital through the year who are discharged to a care home*" (Scottish Government, 2015c)

This measure is 'under development' due to concerns about the quality of the underlying data, which is based on hospital admission and discharge coding (Scottish Government, 2015c). It is not intended that this measure will differentiate between short-stays and permanent placements and nor will it evaluate the appropriateness of care home admission (Scottish Government, 2015c). These data are, however, thought necessary to ensure that achieving other indicators, such as reductions in delayed discharges, do not result in additional use of care homes (Scottish Government, 2015c). This emphasises that new care home admission directly from hospital is considered as an important outcome measure for integration in Scotland, although the interpretation is potentially complicated.

Reducing unwarranted variation is identified as a key priority in the "Realistic Medicine" agenda proposed by Scotland's Chief Medical Officer (NHS Scotland, 2015). Identifying and reducing variation largely rests on robust systems of data collection and informed analysis. These data must, however include sufficient information to make valid comparisons across the regions, adjusting for variations in population structure, deprivation etc. Determining what makes variation "unwarranted" requires engagement with practitioners, patients and families. Coupled with this is the need to ensure data are collected on the outcomes which matter to individuals, so that services align to achieve the care individuals want. Although Scotland has robust systems of data collection, which will be discussed in detail in Chapter Seven, questions remain over the accuracy, timeliness and access to these data and the outcomes which can be evaluated at present.

## 1.3 ACUTE HOSPITALISATION OF OLDER PEOPLE

In Scotland in 2015/16 there were 565,344 emergency hospital admissions, with those aged ≥65 accounting for 43% of the total (~243,000) (Information Services Division Scotland and NHS National Services Scotland, 2017d). In England, adults aged ≥65 have more than two million unplanned admissions each year, using 68% of hospital emergency bed days (Imison *et al*., 2012). Alternative services exist in some areas to avoid or prevent acute hospital admission, such as hospital at home and 'step-up' intermediate care services. There is emerging evidence about services to reduce hospital bed use among older adults, with integrated services provided across hospital and community settings thought to be critical (Philp *et al*., 2013). These are not yet widely available, however and most acute care is provided by admission to hospital. This thesis is concerned with admissions to care homes following acute hospital admission, so it is useful to consider why adults are hospitalised, the care received as inpatients and how this can affect their outcomes. The cohort study described in Chapter Five was designed in response to the lack of existing data on the assessments and experiences of older adults in hospital who were admitted to a care home at the time of their discharge.

The reasons for acute hospitalisations among older adults are broad and encompass the spectrum of conditions which commonly require medical attention, including the treatment of infections, cardiovascular and cerebrovascular events, cancers, injuries and poisoning (Wittenberg *et al*., 2015). Recent work conducted by Glasby *et al.* explored the topic of 'inappropriate admissions' and found difficulties in conceptualising and defining these between health and care professionals and older people, with the majority considering hospital care to be appropriate in meeting their needs (Glasby *et al*., 2016). How services could or should be configured to meet the needs of older people is a vast area for policy, research and practice and attention here will focus on the current dominant model.

### *1.3.1 In-hospital care*

The model of care received during an older person's admission is recognised as an important determinant of their outcomes. Comprehensive Geriatric Assessment (CGA) is defined as a:

> *"… multi-dimensional, multi-disciplinary diagnostic and therapeutic process conducted to determine the medical, mental, and functional problems of older people with frailty so that a co-ordinated and integrated plan for treatment and follow-up can be developed*" (Ellis *et al*., 2017).

Data from 16 randomised controlled trials confirmed that receiving CGA increased the likelihood of an individual being alive and living at home three to twelve months after discharge (Risk Ratio (RR) 1.06, 95% Confidence Interval of 1.01 to 1.10) (Ellis *et al*., 2017). Such evidence supports the need for organised, specialist inpatient geriatric medical care, first proposed by Marjory Warren in the 1940s (Warren, 1943, Warren, 1946). Her observations concerning the benefits of such care to older people have been confirmed in robust clinical trials. The focus now must be on how to most effectively deliver CGA in the pressurised acute NHS systems of the 21st century, gathering evidence around the process and not simply the outcomes.

There is also a growing recognition that in-hospital factors and processes can worsen outcomes for older people. Two timely examples include sedentary behaviour and boarding. Sedentary behaviour is recognised as a significant problem in older people outwith inpatient settings (Leask *et al*., 2015), and is thought to be highly prevalent among hospital inpatients. However, it is amenable to intervention if concerted multicomponent intervention is used (Liu *et al*., 2018). Boarding is the practice where patients receive care in areas of the hospital which are designed and staffed for those with different care needs (Beckett, 2013). It has become common in hospitals across the UK and is considered as a marker of "*suboptimal care*" (Beckett, 2013). Older people are particularly at risk from the adverse effects of boarding, due to their physical frailty, cognitive impairments and need for continuity of care (McMurdo and Witham, 2013). These examples reinforce the need for effective, patient-focused health services research within geriatric medicine to ensure that the care provided to older adults in hospital is based on evidence of effectiveness and deleterious processes are identified and prevented. It is also important to identify those in the care system who are most vulnerable, so their needs can be addressed.

### *1.3.2 Cognitive impairment*

Cognitive impairment, both acute and chronic, is highly prevalent in older adults admitted to hospital (Goldberg *et al*., 2012) and often unrecognised (Jackson *et al*., 2017). Estimates of prevalence vary depending on the methodology used. Data from NHS Fife identified a cognitive spectrum disorder (defined as known dementia, delirium, delirium superimposed on known dementia and unspecified cognitive impairment) in 38.5% of medical admissions aged over 65 (Reynish *et al*., 2017).

Individuals with cognitive impairment are recognised as being at increased risk of adverse events during their inpatient stay (Watkin *et al*., 2012). The mechanism of this increased risk is not fully understood, but it is suggested that it is related to inadequate assessment and treatment, inappropriate interventions, discrimination, low staffing and lack of staff training (George *et al*., 2013). Staff caring for individuals with cognitive impairment require training and support to help them develop the skills and resilience needed to deliver care which supports the needs of the individual and protects them from emotional burnout (Clissett *et al*., 2014). At present however, many healthcare staff feel ill-equipped to care for such patients, reporting that their lack of knowledge and support made them feel stressed and dissatisfied with their role (Griffiths *et al*., 2014). These feelings can be manifest and can compound the often negative experiences of in-hospital care reported by family carers who have a pivotal role in supporting people with dementia (Jurgens *et al*., 2012). Strategies to help improve this include effective provision of information to carers and offering them opportunities to participate in care during the hospital stay (Jurgens *et al*., 2012). The need to value and work with family carers has been recognised in non-cognitively impaired older adults, acknowledging their pivotal role in organising and supporting the person beyond their in-hospital stay (Lowson *et al*., 2013). Hospital staff must develop a greater appreciation of the impact that hospital admission can have on the individual and work to improve in-hospital services to address current deficiencies.

### *1.3.3 Outcomes of acute hospitalisation*

Loss of independence in activities of daily living is also recognised as an adverse outcome following hospital admission, with increasing risk in older patients (Covinsky *et al*., 2003). Individuals whose cognitive function worsens in hospital are at particular risk of losing functional abilities (Zisberg *et al*., 2016). Changes in functional ability can lead to individuals requiring additional support when they are discharged, to try to regain these abilities or to provide long-term assistance.

It is also recognised that a proportion of older adults admitted to hospital will not be able to return to their previous residence and will require long-term care (Bradshaw *et al*., 2013). Identification of more complex cases, including those likely to require long-term care placement, is thought to be beneficial, but the ability to predict this need varies among clinicians (Hickam *et al*., 1991). An alternative approach seen in the literature evaluating risk prediction tools is to use a composite outcome of 'poor outcome' which includes death and care home admission (Edmans *et al*., 2013). This approach is of limited usefulness when communicating with patients and families by conflating two very different outcome measures. Furthermore, it is not useful for

service planning as the needs of those surviving and requiring care home admission are significant.

A cohort study of 10,743 inpatients in 25 Scottish hospitals was conducted using routinely-collected national data (Clark *et al.*, 2014). This found that over a third of those in hospital died within one year and that those aged >85 years were at significantly increased risk of death (45.6% *versus* 13.1% in those under 60). Furthermore, men, those living in deprived areas and those in medical specialties were also at increased risk of death. Although it would be anticipated that hospital inpatients are at significant risk of death, these data are powerful in quantifying that risk, in particular highlighting that many of the older people in hospital are in their last year of life. Recognition of prognosis can help be a prompt to support individuals and their families in decision-making and care planning which is realistic and shaped by individual preferences.

### *1.3.4 Care of Older People in Hospital Standards*

As part of an organised national improvement strategy led by Health Improvement Scotland, standards have been developed around the care of older people in hospital. These 16 standards incorporate assessment and management of core clinical problems including delirium, dementia, frailty and falls (Healthcare Improvement Scotland, 2015). They also include organisational factors around ensuring individuals are cared for by specialist clinicians, in dedicated wards and have access to rehabilitation, support and effective discharge planning (Healthcare Improvement Scotland, 2015). Finally, the standards enshrine the rights of older people to be involved in decisions about their care, have significant others included and be supported in periods of transition (Healthcare Improvement Scotland, 2015). The standards contain detailed information for staff and for the organisation to explain their meaning (Healthcare Improvement Scotland, 2015) and are used as part of the inspection programme conducted in Scotland's hospitals.

## 1.4 DISCHARGE PLANNING

### *1.4.1 What is discharge planning and what is the standard of care?*

Discharge planning is the process of establishing what care and services an individual needs in order for them to be discharged from hospital (Care Information Scotland, 2017b). It is recognised that discharge takes place as part of a complex organisational system within health and social care which results in significant variations in care (Laugaland *et al*., 2014).

In clinical trials, early discharge planning has been shown to be effective in reducing hospital readmissions, although current evidence does not demonstrate reductions in length of stay or satisfaction with discharge planning (Fox *et al*., 2013). In this context 'early' was where planning commenced while the individual was still considered to be in the acute phase of their illness (Fox *et al*., 2013). The impact of early discharge planning on care home admission has not been systematically evaluated. It is reasonable to anticipate that where an individual's care has been well-organised and communicated, it may reduce the likelihood of them needing to return to hospital. It is now recommended that discharge planning should begin from the time of

admission to hospital with the setting of estimated discharge dates being standard practice (Joint Improvement Team, 2015).

### *1.4.2 What are the barriers to effective discharge planning?*

Discharge planning is challenging, particularly in the acute hospital setting. Acute hospitals are under considerable pressure to shorten length of stays and avoid delays associated with discharges which are more complex (Nardi *et al*., 2007). Staff describe feeling pressure from conflicting goals and the concern that the urgency to discharge people from hospital can leave patients 'systematised' without scope to individualise practice (Connolly *et al*., 2009). Research involving specific professional groups identified that nurses often feel ignored and even invisible in discharge planning processes (Atwal, 2002, Nosbusch *et al*., 2011). This was further emphasised when looking at the MDT dynamics and the sometimes unequal voices among health and social care professionals (Atwal and Caldwell, 2005). Allowing for a more even distribution of staff views and reducing the dominance of medical staff within the MDT has been shown to be beneficial in discharge decision-making (Gair and Hartery, 2001). There was evidence of patients being excluded from active decision-making and of different priorities between patients and staff in discharge planning (Huby *et al*., 2007). It has even been argued that systems of discharge decision-making actively prevent older people expressing their views and that this encouraged healthcare professionals to avoid engaging directly with patients (Huby *et al*., 2004). If older adults are to be able to care for themselves after discharge, they need to be able to express and address their concerns to enable individualisation of care (Gabrielsson-Jarhult and Nilsen, 2016).

Discharge planning for people with dementia has been highlighted as a particular area of concern, with inadequate discharge planning arrangements (Chenoweth *et al*., 2015) and a lack of involvement of and communication with family carers (Fitzgerald *et al*., 2011). An additional concern is when differences in opinion arise between the person with dementia and/or their family or the MDT (Brindle and Holmes, 2005). These differences must be acknowledged and addressed, using assessments of capacity and involvement of specialist practitioners if differences cannot be resolved (Brindle and Holmes, 2005, Greener *et al*., 2012).

## 1.5 DELAYED DISCHARGE

Delayed discharges, also known as delayed transfers of care, are the terms used to describe:

> "*… a hospital inpatient who is clinically ready for discharge from inpatient hospital care and who continues to occupy a hospital bed beyond the ready for discharge date*"
> (Information Services Division Scotland and NHS National Services Scotland, 2016c).

The topic has attracted significant interest, usually framed around the economic implications, estimated at £820 million per year for 2.7 million 'bed days' occupied by older people not requiring acute care (National Audit Office, 2016). The average cost per patient per day of delayed discharge is £233 (Information Services Division Scotland and NHS National Services Scotland, 2017c). It is increasingly recognised that delayed discharges affect the whole hospital system, resulting in overcrowding and boarding in the Emergency Department as there are no

available beds for those requiring admission (Mustafa *et al*., 2016). Similarly, rates of delayed discharge from acute services should be a prompt to review the whole system of care, ensuring there has been adequate investment in so-called 'upstream' services including rehabilitation, intermediate and transitional care (Godfrey and Townsend, 2009).

In Scotland in 2016/17 the average proportion of bed days occupied by patients whose discharge is delayed was 8.2%, but this ranged from 3.5 to 28.6% by Health Board area (Information Services Division Scotland and NHS National Services Scotland, 2017c). The daily average rate of delayed transfers of care in England is 14.9 per 100,000, but this varies from 5.6 to 17.3 across the regions (NHS England, 2017). National standards for reducing delays and accepted timeframes have shifted radically over the past decade. Targets are now focused on discharging individuals within a period of 72 hours from being ready, where previously this could take up to six weeks (Information Services Division Scotland and NHS National Services Scotland, 2016d).

In Scotland, in addition to monthly online reporting (Information Services Division Scotland and NHS National Services Scotland, 2017b), delayed discharge is also being included in the evaluation of health and social care integration in two new indicators:

> "*19. Number of days people spend in hospital when they are ready to be discharged.*
>
> *22. Percentage of people who are discharged from hospital within 72 hours of being ready.*" (Scottish Government, 2015c)

Individuals in interim beds, usually care homes, awaiting placement in their chosen care home and those receiving intermediate care in a non-acute hospital setting are not included in delayed discharge data (Information Services Division Scotland and NHS National Services Scotland, 2016d). While data from Scotland show that the number of bed days occupied by those experiencing delayed discharges are falling (Information Services Division Scotland and NHS National Services Scotland, 2017c), English data suggest a rise in delays (NHS England, 2017). English data specifically report whether health or social care are considered to be responsible for the delay, reflecting arrangements for charging social services when delays are attributed to social care (NHS England, 2017).

### *1.5.1 Why do delayed discharges occur?*

The term 'delayed discharge' is applied to all of the possible reasons for delay. In 2016/17 on average 27% of delays in Scotland each month were for individuals awaiting care home availability (Information Services Division Scotland and NHS National Services Scotland, 2017c). Separated from these data are complex cases, termed 'code nine' cases, where an individual's discharge is considered outwith the control of the Health Board or Local Authority, often as a result of specialist needs or issues around Adults with Incapacity (AwI) legislation , estimated to represent 21% of cases monthly (Information Services Division Scotland and NHS National Services Scotland, 2017c). This latter group may also include individuals who are moving to care homes, but no breakdown of reasons is available to fully explore this.

In England, waiting for a package of care at home accounted for the single largest proportion of delayed days (20.3%), followed by awaiting non-acute NHS care (17.1%) and completion of

assessment (16.9%) (NHS England, 2017). Waiting for nursing home placement, however, accounted for 15.2% and residential placement for 10.3%. Waiting for long-term care would therefore represent the largest group if these were aggregated (NHS England, 2017).

### *1.5.2 What are the experiences of those who are delayed?*

A large UK literature review identified in 2006 that much of the delayed discharge literature failed to incorporate the perspectives of the patients affected (Glasby *et al*., 2006). Subsequent work has raised concerns that older people delayed in hospital felt disempowered and not involved in the process, and desperately sought continuity in care and planning (Swinkels and Mitchell, 2008). Furthermore it has been suggested that individuals and their carers are "*at their most vulnerable yet receive the least care from the formal care system*" while waiting (Kuluski *et al*., 2017). It has also been observed that a potential consequence of the pressure to reduce delays can be to exclude older people from discharge discussions. This can result in them feeling unwelcome, leading to feelings of guilt and contributing to dissatisfaction among healthcare professionals (Ekdahl *et al*., 2012). Such consequences need not be inevitable, but require a balancing between the need to improve patient flow and ensure practice is person-centred. It is also important that the healthcare system and its staff recognise the ongoing needs of the individual and their family, even if medical care is no longer the focus, so that such individuals are not seen or treated as a 'problem'.

## 1.6 MOVING ON FROM THE ACUTE HOSPITAL SETTING

For individuals who are ready to leave acute hospital care, but have ongoing needs, there is currently a range of formal models of care, although provision varies across the UK. In practice these overlap between provision for those who require ongoing medical care and those whose needs are only for social care services.

**Rehabilitation** has been defined as

> "*… a process aiming to restore personal autonomy in those aspects of daily living considered most relevant by patients or service users and their family carers*" (Sinclair and Dickinson, 1988).

Rehabilitation is a multi-disciplinary process which, in the context of this Chapter, is considered as an inpatient model of care, delivered in acute and community or rehabilitation hospital settings, although it is recognised the scope of practice can be much broader (Stott and Quinn, 2017). Rehabilitation services have been evaluated in care home settings, reducing time spent in hospital but not reducing rates of eventual care home admission (Fleming *et al*., 2004). Inpatient rehabilitation for older people is an effective model to improve functional status, reduce care home admissions and reduce mortality (Bachmann *et al*., 2010).

**Intermediate care** is defined as

> "*… a range of integrated services to promote faster recovery from illness, prevent unnecessary acute hospital admission and premature admission to long-term residential care, support timely discharge from hospital and maximise independent living*" (Department of Health, 2009).

The scope of intermediate care encompasses crisis response, bed-based services, home-based services and reablement (NHS Benchmarking Network, 2015) – in this context the last three may apply to individuals leaving hospital, depending on availability in their area. The NHS in England collects high-quality data in the form of its national audit of services, collecting data on effectiveness including maintaining or reducing dependency and return to previous residence with respect to returning home in addition to service user feedback, access and staffing (NHS Benchmarking Network, 2015).

Innovative models of care include **early discharge hospital at home** services and **discharge to assess**. The former provides ongoing medical care and rehabilitation in an individual's own home. The trials which have been conducted have included heterogeneous populations including those following stroke, elective surgery and a mixture of medical conditions – with evidence of reductions in length of stay and similar patient outcomes (Gonçalves-Bradley *et al*., 2017). The Cochrane review found that early discharge hospital at home may reduce the risk of requiring care home admission, but the evidence was considered of low certainty (Gonçalves-Bradley *et al*., 2017). Discharge to assess takes the rehabilitation and therapy assessment components of care out of the hospital setting, conducting them in an individual's home. It also reduces length of stay and is thought to achieve more accurate assessment of individual needs based on performance in their own environment, rather than an acute hospital setting (Offord *et al*., 2017).

**Reablement** services vary in scope and level of provision, but essentially are short-term support to help individuals return to the previous level of functioning after an acute hospital admission (Care Information Scotland, 2017a). This may involve care staff, occupational therapy and physiotherapy input, as needed. In England, the first six weeks of reablement are provided without cost to the individual (Social Care Institute for Excellence, 2012).

**Care package**: individuals may require ongoing social care support at home, either a restart of previous services or initiation of new services following their hospital admission. The services provided are described in **Table 1.1** and broadly help to support individuals in their basic activities of daily living while remaining in a private residence. Data around care in the community tends to be gathered on the basis of the hours of care received. In 2016 there were 59,780 people in Scotland receiving Home Care services, totalling 676,500 hours per week (Scottish Government, 2017c). The Personal Social Services Research Unit estimates that home care for older people costs on average £180 per week (£9,360 p.a.), although this can be as high as £303 per week (£15,756 p.a.) (Curtis and Burns, 2016).

Sheltered housing, extra-care housing and other models of supported accommodation are further significant contributors to the care sector for older people. These options are typically accessed when individuals are in the community, rather than as a primary discharge destination. Detailed discussion of their organisation and advantages is beyond the scope of this work.

**Hospital-based complex clinical care (HBCCC)**: was introduced in June 2015, replacing the previous system, known as NHS Continuing Care, in which the costs of care are met by the NHS rather than the individual or their Local Authority (Scottish Government, 2015d). Entitlement to HBCCC is determined by the patient's responsible consultant with advice from the MDT,

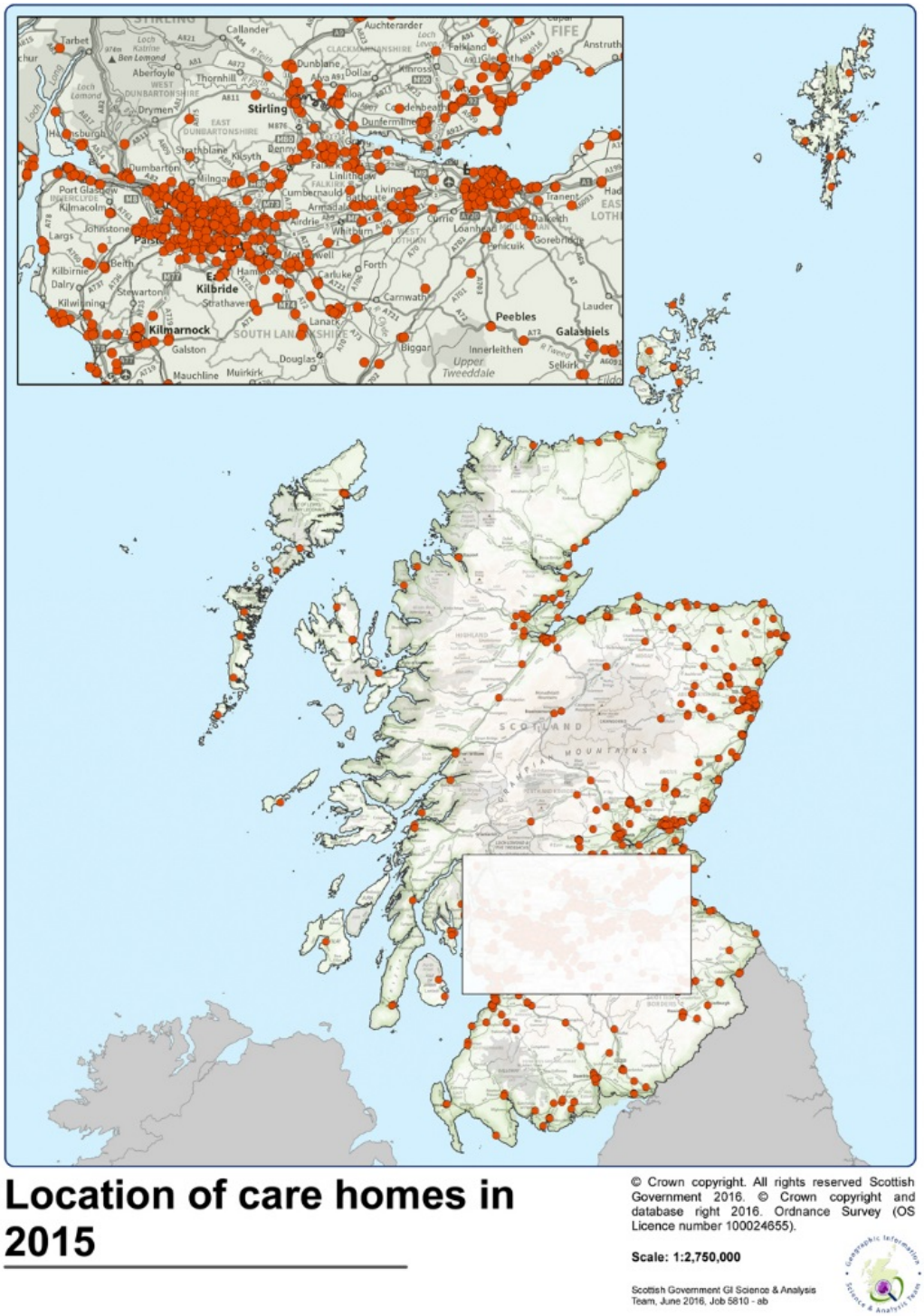
agreeing that the patient's care needs cannot properly be met in any setting other than a hospital (Scottish Government, 2015d). Most of those receiving HBCCC have a mental health diagnosis (Scottish Government, 2017b). HBCCC may be used for more detailed assessment and management of complex older adults who may remain there or subsequently be discharged to a care home setting.

## 1.7 CARE HOMES

Care homes in the UK have a vital and often undervalued role in caring for the increasingly complex, frail adults whose needs cannot be adequately addressed in the community (Rogers, 2015). Since the 1980s, the independent care home sector has grown rapidly, largely in response to the closure of long-term NHS beds to care for older people (Impallomeni and Starr, 1995, Sutaria *et al*., 2017). In England, 10,331 (90%) of all care homes are now independently owned, including for-profit and not-for-profit organisations (Iliffe *et al*., 2016). In Scotland, 1,008 (86%) are independently owned (Information Services Division Scotland and NHS National Services Scotland, 2016a). More in-depth information about the characteristics of Scottish care homes and their residents is presented in Chapter Nine.

**Figure 1.2** summarises the distribution of all adult care homes across Scotland. There seems to be a trend emerging of a reduction in overall care provision in Scotland. Since 2006 the number of registered care homes has reduced by 20% from 1,470 to 1,175 in 2016 (Information Services Division Scotland and NHS National Services Scotland, 2016b). There is also a downward trend in the availability of care home places in Scotland, down 4% since 2006 from 43,311 to 41,461 places (Information Services Division Scotland and NHS National Services Scotland, 2016b). Most of this has been driven by a reduction in numbers of Local Authority and voluntary sector homes (Information Services Division Scotland and NHS National Services Scotland, 2016b). There are aspirations that society can reduce the need for institutional care, due to a desire to empower more individuals to remain at home and concerns about the costs of formal care. The reduced availability of care may become problematic when faced with the demographic and social changes described in Section 1.1. The recent Cognitive Function and Ageing Study cohort analysis also identified the UK as likely to need more care home places (Kingston *et al*., 2017).

**Figure 1.2: Map of the distribution of care homes in Scotland in 2015** (Ordnance Survey and Scottish Government Geographic Information Science & Analysis Team, 2016)




### *1.7.1 Who lives in UK care homes?*

The care home population has become more medically complex and physically dependent (Green *et al.*, 2017, Matthews *et al.*, 2016). This poses significant challenges for the staff providing care in this setting. Cohort study data have identified a high prevalence of cognitive

impairment, comorbidity, polypharmacy, immobility, dependency and incontinence among UK care home residents (Bowman *et al*., 2004, Gordon *et al*., 2014). Care homes are also increasingly likely to provide end-of-life care and are now the place of death for 21.2% of adults in England & Wales (Bone *et al*., 2018). Delivering high-quality care to meet the needs of current and future care home populations is likely to require effective collaboration between health and social care practitioners and appropriate training and support for care home staff to manage the complex needs of residents. There have been no specific published data from Scotland characterising the care home population and their care needs.

### *1.7.2 Costs of care home placement*

Funding for care home placement in the UK is means tested. In Scotland, Local Authority funding is available for those with <£16,000 in savings and property (Information Services Division Scotland and NHS National Services Scotland, 2015). Their pensions and any other income will be used to pay for the costs of the care home, supplemented by their Local Authority (Information Services Division Scotland and NHS National Services Scotland, 2015). Self-funded residents, defined as those with >£26,000 of savings and property, are liable for the entire cost of the placement, excluding the amount received in their free personal care allowance and free nursing care allowance if they are assessed as requiring it (Information Services Division Scotland and NHS National Services Scotland, 2015). Charges for care homes vary widely across Scotland, with average annual charges in 2015 of £26,416 - £40,300, depending on level of care and public or private funding status (Information Services Division Scotland and NHS National Services Scotland, 2015). Average care home costs in England vary by region from £26,572 in the North West for a care home without nursing to £54,132 per year in the South East for a care home with nursing (Laing & Buisson, 2017). Significantly, individuals funding their own care usually pay a higher weekly charge than those who are funded by the State.

### *1.7.3 Attitudes to care homes*

Attitudes towards care homes in Western society are mixed. A cohort study of hospitalised adults with serious illnesses found a third considered requiring nursing home care to be worse than death (Rubin *et al*., 2016). Even this perception speaks to an undercurrent of attitudes which consider the dependency associated with care homes as a negative outcome. Some of this reaction is understandable in the face of negativity in coverage with respect to the care received and the variations in quality evident in the UK care home sector (Care Quality Commission, 2017). Those with direct professional or personal experience often describe care home admission as a positive outcome for an individual, particularly when contrasted with the often lonely and isolated situation increasingly common in society. For those with significant care needs, care homes can provide a safe and supportive environment, with evidence that individuals can flourish in this setting (Bockerman *et al*., 2012, Minney and Ranzijn, 2016). Furthermore, care delivered in a care home setting has been associated with a four-fold increase of dying comfortably compared with dying in hospital, assessed by interviews with relatives and carers (Fleming *et al*., 2017). Addressing poor care and improving the quality across the care

home sector is a priority, but it is also important to affirm the value of care homes in supporting the most complex and vulnerable.

## 1.8 CARE HOME ADMISSIONS AND TRANSITIONS

Moving into long-term institutional care is a major decision for any individual and one which comes with significant personal and economic implications (Wubker *et al*., 2015). The James Lind Alliance Priority Setting Partnership for Dementia, incorporating the views of patients, families, practitioners and researchers, identified research to understand the optimal timing for moving into a care home as one of ten priority questions for dementia researchers (Kelly *et al*., 2015). Admission to hospital and increasing frequency of Emergency Department attendances are associated with provoking thoughts about requiring institutional care among older adult homeowners or tenants (Dubois *et al*., 2008). The study did not consider if these thoughts were acted upon (Dubois *et al*., 2008). Interactions with acute hospital services are likely to be important predictors of risk of care home placement, which could help to identify individuals who may require support.

### *1.8.1 Predictors of care home admission*

Most published evidence on care home admission has focused on community-dwelling adults and those with dementia, rather than considering hospitalised older adults.

In a review of 36 population studies of adults >65 years, institutional care admission was associated with being older, low self-rated health, functional impairment, dementia, prior nursing home placement and polypharmacy (Luppa *et al*., 2010). A large US meta-analysis identified activities of daily living dependency, cognitive impairment and prior nursing home use as predictors of care home admission increasing risk two- to three-fold in community-based samples over longitudinal follow-up (Gaugler *et al*., 2007). Gender differences have been identified in factors predicting nursing home placement (Luppa *et al*., 2009). A systematic review which included 11 studies identified that being incontinent, unmarried, living alone and not in their own home were higher risk predictors for men than for women (Luppa *et al*., 2009).

The RightTimePlaceCare study was a prospective cohort study set in eight European countries which incorporated quantitative and qualitative methods involving people with dementia and their carers (Verbeek *et al*., 2012). This concluded that in community-dwellers with dementia, caregiver burden was the most consistent predictor across all included countries, but that dependence in activities of daily living was also significant (Verbeek *et al*., 2015). Critically, this study also identified significant variation across different countries, suggestive of context-specific mechanisms which add to the complexity of generalising findings (Verbeek *et al*., 2015). Interviews with informal caregivers also found variations in attitudes and practice between countries (Afram *et al*., 2014). However, neuropsychiatric symptoms, cognition, dependency and caregiver burden were common reasons for the need for institutional care (Afram *et al*., 2014). The most recent systematic review of predictors of nursing home placement for people with dementia concluded poorer cognition and behavioural and psychological symptoms of dementia were the most consistent predictors of increased risk (Toot *et al*., 2017).

An approach to predictors of institutional care comes from Luppa *et al.* who describe a conceptual framework of predisposing, need and enabling variables in predicting institutionalisation in people with dementia. Their model encapsulates the complexity of the decision-making and the interaction between the socioeconomic and relationship characteristics of the individual and the family, the stressors they may experience, the resources they can draw upon both personally and in the community and how all of these contribute to the decision (Luppa *et al*., 2008). Such an approach for hospital inpatients could be helpful for multidisciplinary decision-making.

The process of being discharged to long-term care from hospital settings is comparatively under-researched. No relevant systematic reviews or meta-analyses focusing on care home admission directly on hospital discharge were identified. There is a systematic review which looked at the case-mix and outcomes following hospitalisation, including discharge destination (Campbell *et al*., 2004). This identified five relevant papers and found that functional status, cognition, diagnosis or presenting illness and age were statistically significant predictors of discharge destination (Campbell *et al*., 2004), although the destination these predicted is not specified. It is not known whether the predictive factors are the same or different in people admitted to a care home directly following an acute hospital admission. Although the hospital admission is a small part of the individual's life and care, it is potentially significant given the issues discussed in Section 1.3. Hospital admission itself has been described as being associated with premature admission into long-term care (Joint Improvement Team, 2015, Alzheimer's Society, 2011). Chapter Three reports the findings of the systematic review of predictors of care home admission directly after hospitalisation. Understanding the factors which predict need for institutional care admission directly from the acute hospital setting may help in redesigning services and providing support for those experiencing this transition.

### *1.8.2 Transition to care home*

Moving into a care home has long been considered a more complex phenomenon than the term 'admission' suggests. Instead it is recognised as a major transition in life, with practical and psychological consequences for the individual and their carers (Zarit and Whitlatch, 1992, Johnson and Bibbo, 2014). Individuals who make this transition from hospital may have different experiences from those who go directly from their own home. Specific challenges in the hospital setting include the time and availability of staff to discuss issues with patients, level of patient and family/carer involvement in the decision to move into care, recognition by hospital staff of the life-changing nature of the decision and potential for bereavement-type reactions (Cotter *et al*., 1998). The experiences of those making this transition has had little research attention. Chapters Five and Six describe local practice and the experiences of individuals, families and staff regarding care home transitions from hospital.

## 1.9 NEW CARE HOME ADMISSION AS AN OUTCOME MEASURE

New care home admission has utility as an outcome measure for use in research and practice. It is a meaningful outcome which reflects a life-changing experience for the individuals affected and has an impact on wider society. It could potentially be used to represent advanced

dependency and the need for 24-hour care, support and supervision. Variations in this outcome may simply reflect differences in the populations admitted to hospital, but could also provide useful insight into in-hospital care, safety, effectiveness and decision-making processes.

The desire to better understand how and why individuals are admitted to care home after an acute hospital admission can broadly be divided into two overarching aims: those to improve care for individuals, and those to inform and develop services for society. To describe and understand the needs of this vulnerable and complex population systematically could ultimately help to ensure we have a care home sector which is trained, staffed and supported to meet those needs. For society the benefits are further sub-divided into: clarifying resource use; identifying and addressing regional variation; benchmarking services to compare and develop the most effective models of care; developing interventions to prevent, reduce or delay the need for care home admission and, ultimately, to inform local and national health and social care planning.

It is not clear, however, whether current UK data systems allow for the routine evaluation of new care home admission after hospitalisation. In Scotland, concerns have been raised about the quality of hospital data on care home residents (Scottish Government, 2015c). Recent work in England found no care home residents correctly identified as such in hospital admission records, they were coded as admitted from 'usual place of residence' without differentiation between private homes and care homes (Housley *et al*., 2018). Therefore, in order to pursue research into care home admissions following hospitalisation, the first step is to identify existing data sources on care home residency, characterise the data collected and evaluate their quality. In Chapter Eight, analysis is reported of hospital and patient registration data quality for identifying care home residency. Chapter Nine describes the completeness and components of the Scottish Care Home Census data, before presenting a proposal to characterise and use routinely-collected linked health and social care data to investigate care home admissions following hospitalisation across Scotland.

## 1.10 A MIXED METHODS APPROACH

This thesis uses a mixed methods approach, which has been described as research which:

> *"… combines elements from both qualitative and quantitative paradigms to produce converging findings in the content of complex research questions.* (Lingard *et al*., 2008)"

Quantitative health research:

> "*… focuses on measuring quantities and relationships between attributes, following a set of scientifically rigorous procedures. It collects highly structured data and is deductive in approach*"(Bowling, 2005).

Qualitative health research:

> "… *aims to answer 'what', 'how' or 'why' questions about social aspects of health, illness and health care*" (Green and Thorogood, 2011b).

The inclusion of different research methodologies offers a range of different benefits: triangulation or convergence of ideas arising from different forms of data collection; expansion of quantitative findings from qualitative insights and *vice versa*; exploring the subject in greater detail by gaining a more comprehensive picture of the phenomenon under investigation (Doyle

*et al*., 2016). Critical to the success of a mixed methods approach is the integration of data from the different aspects of the work to enhance the meaning of the findings and thus potential learning (O'Cathain *et al*., 2010). Integration of the positive elements of different methods, retaining awareness of the limitations of each, is essential for effective mixed methods work (Lingard *et al*., 2008).

The topic of interest in this thesis is pragmatic. It concerns the patterns, predictors and outcomes for individuals admitted to an acute hospital and their admission to care homes. In spite of this being a common outcome to hospital practitioners, it has been under-researched. Variations in experience are recognised and reflect underlying differences in practice and the organisation of services. Therefore, several different methodological approaches have been used to try to address the research questions. This has required an inter-disciplinary approach, with collaborators in nursing, social sciences, data analysis and statistics (see Acknowledgements).

The quantitative analyses (Chapters Three, Five, Eight and Nine) and qualitative analyses (Chapters Four and Six) are presented here as a portfolio of work adding to the understanding of new care home admission following hospitalisation. Chapter Ten integrates the insights from all the methodological approaches, considering how to investigate this topic further.

## 1.11 AIM & OBJECTIVES OF THE THESIS

**Aim**: To develop an understanding of new care home admission following acute hospitalisation.

**Objective 1**: To identify the predictors of care home admission following acute hospitalisation identified in the published research literature [Chapter Three].

**Objective 2**: To develop methods to create a search filter to improve identification of the existing care home research literature, accounting for the international variation in terminology used for 'care home settings' and their services [Chapter Four].

**Objective 3**: To describe current practice around care home admission from hospital using data from a retrospective cohort study using case-note methodology enriched by the experiences and perspectives of stakeholders in the process obtained through qualitative case-study research [Chapters Five & Six].

**Objective 4**: To identify care home residents in routinely-collected linked health data sources and describe the feasibility of using such data to identify care home residency [Chapter Eight].

**Objective 5**: To explore the Scottish Care Home Census as a novel national social care data source, describing the data on care home admissions and the potential added value which could be obtained through health and social care data linkage [Chapter Nine].

The thesis is presented in three parts. These move the content from exploring existing research findings, through an in-depth analysis of practice in one hospital, broadening to look at how this question can be examined at scale across Scotland.

### *1.11.1 Part One: Identifying relevant research*

This begins with a review of tools to assess quality when conducting systematic review (Chapter Two). Chapter Three uses systematic review and meta-analysis of quantitative data obtained from observational studies to summarise the published knowledge on predictors of care home admission from hospital. Chapter Four proposes a methodological approach to develop a search filter to improve the ability to identify published research relevant to care homes, including the findings from qualitative data obtained in a survey of care home researchers.

### *1.11.2 Part Two: Exploring current clinical practice*

Chapter Five describes a retrospective cohort study of 100 people discharged to a care home from one acute teaching hospital, in which descriptive data were collected, primarily as hypothesis generating, about local clinical practice. Chapter Six uses qualitative data from one case study, to explore the lived experience of a patient, his family and the practitioners involved in his care.

### *1.11.3 Part Three: Harnessing routinely-collected data*

Chapter Seven provides an introduction to health and social care data linkage, with a focus on Scottish data sources. Chapters Eight and Nine are secondary analyses of routinely-collected health and social care quantitative data from NHS Fife and Tayside and the Scottish Care Home Census respectively, to understand the potential and limitations of these data to describe practice in Scotland

Together, these approaches provide insights into this complex subject area and identify targeted areas for future applied research, discussed in Chapter Ten.

# PART ONE

# Identifying Relevant Research

**Chapter Two**
Quality Assessment Tools for Systematic Review

**Chapter Three**
Predicting Discharge to Care Homes from the Hospital Setting: A Systematic Review & Meta-analysis

**Chapter Four**
Identifying Care Home Research: Methods to Develop a Search Filter and a Survey of International Researchers

# CHAPTER TWO
# Quality assessment for systematic review

## 2.1 INTRODUCTION

In preparing for a systematic review to explore research into the predictors of care home admission from hospital (Chapter Three) – which would include observational studies, rather than clinical trials – it became clear that a method of assessing risk of bias in these studies would be required. A literature search was performed to help appreciate the methodological considerations and available tools. This Chapter will discuss non-randomised and observational study designs before comparing a range of common tools used to evaluate their quality. It will then discuss the choice of tool for use in the systematic review described in Chapter Three and introduce the approach used to evaluate the overall quality of evidence gathered. This chapter includes material from a review article which provides a guide for clinicians and researchers on quality assessment in ageing research (Harrison *et al*., 2017b).

## 2.2 NON-RANDOMISED AND OBSERVATIONAL METHODS

A key initial aspect was defining non-randomised and observational studies and appreciating the overlap between them. The terms 'non-randomised' and 'observational' are not interchangeable. Although observational study designs can all be described as non-randomised, not all non-randomised studies are observational in their conduct.

A non-randomised study can be defined as:

> *"… any quantitative study estimating the effectiveness of an intervention that does not use randomization to allocate units to comparison groups. This included studies where allocation occurs in the course of usual treatment decisions of peoples' choices, i.e. studies usually called observational."* (Reeves *et al*., 2011)

Non-randomised studies to evaluate an intervention are primarily conducted where randomisation is not considered to be pragmatic or possible, often due to ethical concerns (Ijaz *et al*., 2014). They can also be used in exploratory study designs, where the aim of the study is to identify associations between intervention(s) and outcome(s) (Reeves *et al*., 2013). Designs can include: non-randomised controlled trials; controlled before-and-after studies; interrupted-time-series studies and; historically controlled studies (Reeves *et al*., 2011).

Observational studies include cohort and case-control designs and can all be described as non-randomised. Observational studies are used where randomised trials are not feasible or ethical, or to provide initial evidence for aetiology and prognosis which can later be tested in randomised trials. Cohort studies typically include at least two groups which differ in their exposure and follows them over time to see how this affects the development of an outcome (Greenhalgh, 1997). Case-control studies include individuals with a disease as 'cases' matched to individuals without that disease who are considered 'controls', to try to understand factors associated with the development of the disease (Greenhalgh, 1997).

## 2.3 ASSESSING METHODOLOGICAL QUALITY

There is a lack of consensus around the use of tools to assess the methodological quality of non-randomised and observational studies (Sanderson *et al*., 2007). Over the past decade much of the focus has been around tools to evaluate risk of bias. In a 2003 Health Technology Assessment, 194 tools were identified which had been used to assess quality in non-randomised intervention studies, of which only six were deemed suitable for use in systematic reviews (Deeks *et al*., 2003). The inclusion of non-randomised studies in Cochrane systematic reviews has been evaluated (Ijaz *et al*., 2014). Assessment of methodological quality is an established component in Cochrane reviews. A review of methods to assess risk of bias in Cochrane systematic reviews which included non-randomised studies found, however, that assessments were varied and used a range of approaches including: the Effective Practice and Organisation of Care (EPOC) criteria; the Newcastle-Ottawa Scale and; the Downs and Black checklist among others (Ijaz *et al*., 2014). This highlights a common problem in this field whereby there are large numbers of putative tools which lack a robust evidence base to support their use.

The major concern when evaluating the quality of non-randomised intervention studies is the risk of confounding due to selection bias (Valentine and Thompson, 2013). Selection bias can be introduced when the individuals included in the study are thought to differ from the wider population of interest because of how those individuals have been included or selected for, or excluded from, the study. It can be difficult to estimate the impact of this bias on the results obtained and hence to try to adjust for the effect statistically (Valentine and Thompson, 2013). Checklists have been created to support review authors wanting to include non-randomised studies in systematic reviews to help standardise the approach, particularly in Cochrane reviews (Wells *et al*., 2013).

Some of the commonly described tools for assessing the quality of non-randomised and observational studies are outlined below, summarising their advantages and limitations. The components of these tools are compared in **Table 2.1**.

**Table 2.1: Comparing the components of each tool/checklist** (expanded from version in Harrison *et al*., 2017b)

| | **CASP (Critical Appraisal Skills Programme, 2013a)** | **CASP (Critical Appraisal Skills Programme, 2013b)** | **Downs & Black (Downs and Black, 1998)** | **EPOC (Cochrane Effective Practice and Organisation of Care, 2017)** |
|---|---|---|---|---|
| **Study designs** | Case-control studies | Cohort studies | Randomised and non-randomised (including cohort and case-control) | Non-randomised controlled trials and controlled before and after studies |
| **Purpose** | Methodological quality | Methodological quality | Reporting and methodological quality | Risk of bias |
| **Included Domains/Questions** | | | | |
| | 1. Did the study address a clearly focused issue?<br>2. Did the authors use an appropriate method to answer their question?<br>3. Were the cases recruited in an acceptable way?<br>4. Were the controls selected in an acceptable way?<br>5. Was the exposure accurately measured to minimise bias?<br>6. What confounding factors have the authors accounted for? Have they taken account of the potential confounding factors in the design and/or the analysis?<br>7. What are the results of the study?<br>8. How precise are the results? How precise is the estimate of risk?<br>9. Do you believe the results?<br>10. Can the results be applied to the local population?<br>11. Do the results of this study fit with other available evidence? | 1. Did the study address a clearly focused issue?<br>2. Was the cohort recruited in an acceptable way?<br>3. Was the exposure accurately measured to minimise bias?<br>4. Was the outcome accurately measured to minimise bias?<br>5. Have the authors identified all important confounding factors? Have they taken account of the confounding factors in the design and/or analysis?<br>6. Was the follow up of subjects complete enough and long enough?<br>7. What are the results of the study?<br>8. How precise are the results?<br>9. Do you believe the results?<br>10. Can the results be applied to the local population?<br>11. Do the results of this study fit with other available evidence?<br>12. What are the implications of this study for practice? | 1. Reporting: 10 questions<br>2. External validity: 3 questions<br>3. Internal validity – bias: 7 questions<br>4. Internal validity – confounding (selection bias): 6 questions<br>5. Power: 1 question | 1. Was the allocation sequence adequately generated?<br>2. Was the allocation adequately concealed?<br>3. Were baseline outcome measurements similar?<br>4. Were baseline characteristics similar?<br>5. Were incomplete outcome data adequately addressed?<br>6. Was knowledge of the allocated interventions adequately prevented during the study?<br>7. Was the study adequately protected against contamination?<br>8. Was the study free from selective outcome reporting?<br>9. Was the study free from other risks of bias? |

*Table 2.1 continued overleaf*

*Table 2.1 continued*

| | **Newcastle-Ottawa (Wells *et al.*, 2014)** | **Newcastle-Ottawa (Wells *et al.*, 2014)** | **RoBANS (Kim *et al.*, 2013)** | **ROBINS-I (Sterne *et al.*, 2016)** | **RTI Item Bank (Viswanathan and Berkman, 2012)** |
|---|---|---|---|---|---|
| **Study designs** | Case-control studies | Cohort studies | Non-randomised | Non-randomised intervention studies | Observational studies of interventions or exposures |
| **Purpose** | Methodological quality | Methodological quality | Risk of bias | Risk of bias | Risk of bias and precision |
| | **Included Domains/Questions** | | | | |
| | **Selection**<br>1. Is the case definition adequate?<br>2. Representativeness of the cases<br>3. Selection of controls<br>4. Definition of controls<br>**Comparability**<br>1. Comparability of cases and controls on the basis of the design or the analysis<br>**Exposure**<br>1. Ascertainment of exposure<br>2. Same method of ascertainment for cases and controls?<br>3. Non-response rate | **Selection**<br>1. Representativeness of the exposed cohort<br>2. Selection of the non-exposed cohort<br>3. Ascertainment of exposure<br>4. Demonstration that the outcome of interest was not present at start of the study<br>**Comparability**<br>1. Comparability of cohorts on the basis of the design or the analysis<br>**Outcome**<br>1. Ascertainment of outcome<br>2. Was follow-up long enough for outcomes to occur?<br>3. Adequacy of follow-up of cohorts | 1. Selection of participants (selection bias)<br>2. Confounding variables (selection bias)<br>3. Intervention (exposure) measurement (performance bias)<br>4. Blinding of outcome assessment (detection bias)<br>5. Incomplete outcome data (attrition bias)<br>6. Selective outcome reporting (reporting bias) | 1. Bias due to confounding (eight questions)<br>2. Bias in selection of participants into the study (five questions)<br>3. Bias in classification of interventions (three questions)<br>4. Bias due to deviations from intended interventions (six questions)<br>5. Bias due to missing data (five questions)<br>6. Bias in measurement of outcomes (four questions)<br>7. Bias in selection of the reported results (three questions) | 1. Sample definition and selection (six questions)<br>2. Interventions/exposure (one question)<br>3. Outcomes (one question)<br>4. Creation of treatment groups (four questions)<br>5. Blinding (one question)<br>6. Soundness of information (two questions)<br>7. Follow-up (four questions)<br>8. Analysis comparability (three questions)<br>9. Analysis outcome (five questions)<br>10. Interpretation (one question)<br>11. Presentation and reporting (one question) |

### *2.3.1 Critical Appraisal Skills Programme*

The Critical Appraisal Skills Programme (CASP) has developed checklists for use with case-control (Critical Appraisal Skills Programme, 2013a) and cohort studies (Critical Appraisal Skills Programme, 2013b). The case-control checklist has 11 questions and the cohort study checklist has 12, in both cases grouped under three headings: are the results of the study valid?; what are the results? and; will the results help locally? (Critical Appraisal Skills Programme, 2013a, Critical Appraisal Skills Programme, 2013b). Each contains useful signalling prompts beside each question to aid understanding. There are, however, no agreed means of totalling the scores or establishing which items are of greatest importance.

### *2.3.2 Downs and Black Checklist*

The Downs and Black Checklist contains 27 items organised into sections assessing: reporting, external validity, internal validity and power (Downs and Black, 1998). It was created to allow for the evaluation of both randomised and non-randomised studies in healthcare, allowing them to be compared more directly (Downs and Black, 1998). It was developed in 1998 and has been used by authors in their reviews of non-randomised studies (Ijaz *et al*., 2014). No external validations of the tool could be identified, however and the checklist has been found to be time-consuming and difficult to use, particularly if assessors are inexperienced (Reeves *et al*., 2011).

### *2.3.3 Effective Practice and Organisation of Care Criteria*

The Effective Practice and Organisation of Care (EPOC) criteria were developed by the Cochrane EPOC Group and allow for the inclusion of non-randomised controlled trials, controlled before-and-after studies and interrupted-time-series studies in Cochrane systematic reviews (Effective Practice and Organisation of Care (EPOC), 2013). For studies which have a separate control group, they identify nine criteria to assess risk of bias using the standard Cochrane approach of low, unclear or high risk of bias for each of the nine domains and provide narrative guidance to support their application (Cochrane Effective Practice and Organisation of Care, 2017). The EPOC criteria can be used to include randomised trials and non-randomised trials together, evaluating the same risk of bias parameters for each design. For interrupted-time-series studies, seven criteria are identified to assess risk of bias, also with further narrative guidance provided on their application (Cochrane Effective Practice and Organisation of Care, 2017). The EPOC criteria do not allow for the inclusion of cohort, case-control or cross-sectional study designs (Effective Practice and Organisation of Care (EPOC), 2013).

### *2.3.4 Newcastle-Ottawa Scale*

The Newcastle-Ottawa Quality Assessment Scale (NOS) is an eight-item scale with two versions, specific for use with cohort studies or case-control studies (Wells *et al*., 2014). It is freely available on the website of the Ottawa Hospital Research Institute (Wells *et al*., 2014), but has not yet been published in any peer-reviewed publication. The NOS evaluates the domains of selection, comparability and outcome (cohort studies) or exposure (case-control studies). Each item receives a star rating when a factor is present, with a maximum of nine stars available

(Wells *et al*., 2014). No specific numerical value has been assigned to a study being of either high or low quality, although higher scores indicate greater use of favourable methodological aspects. The inter-rater reliability of the NOS has been questioned, however, with concerns that many items rate as either poor or fair (Hartling *et al*., 2013). Similarly, when the scores given by reviewers and authors were compared, authors scored their own papers much more highly, suggesting potential inclusion of information not reported in their manuscript (Lo *et al*., 2014). While authors may be more likely to rate the quality of their work more highly, this again emphasises that inadequate reporting can affect quality assessment and that quality assessment tools should be robust and validated. The overall usefulness of the NOS in distinguishing between studies of high and low methodological quality has been questioned (Stang, 2010, Hartling *et al*., 2013) and its lack of external validation is problematic in evaluating this completely.

### *2.3.5 Risk of Bias Assessment tool for Non-Randomised Studies*

The Risk of Bias Assessment tool for Non-Randomised Studies (RoBANS) is a six-domain tool designed to look at risk of bias alone (Kim *et al*., 2013) and does not consider other aspects which can be considered indicators of study quality. It invites authors to assess: the selection of participants; confounding variables; the measurement of exposure; the blinding of outcome assessments; incomplete outcome data and; selective outcome reporting. Authors must also judge whether there is high, low or unclear risk of bias for each individual domain (Kim *et al*., 2013). It is consistent with the Cochrane Risk of Bias tool and thus simple diagrams can be generated evaluating individual domains. It has been validated by its original authors (Kim *et al*., 2013), but has not yet had a large external validation to establish its usefulness.

### *2.3.6 Risk of Bias In Non-randomised Studies – of Interventions*

In October 2016 a new tool relevant to this topic was published. Risk of Bias In Non-randomised Studies – of Interventions, known as ROBINS-I, is a seven-domain tool the application of which is limited to intervention studies (Sterne *et al*., 2016). Domains are divided into those pre-intervention (bias due to confounding or in participant selection), at intervention (bias in classification of interventions) and post-intervention (bias due to deviations from intended interventions; missing data; measurement of outcomes and; selection of the reported results) (Sterne *et al*., 2016). The tool invites users to assess risk of bias by comparing the conduct of the study they are appraising with what the authors term 'a target trial', defined as:

> *"… hypothetical pragmatic randomised trial, conducted on the same participant group and without features putting it at risk of bias, whose results would answer the question addressed by the non-randomised study of an intervention."* (Sterne *et al*., 2016)

ROBINS-I provides detailed guidance on how to score each domain of bias, determining if the item is of low, moderate, serious or critical risk of bias and includes the response 'no information' where risk of bias evaluation cannot be made using the available data (Sterne *et al*., 2016). It is too early to evaluate the impact ROBINS-I will have on methodological quality assessment in the field and this is likely to be determined by the uptake and usability of the tool.

### *2.3.7 RTI Item Bank*

The RTI item bank on risk of bias and precision of observational studies was published in 2012 (Viswanathan and Berkman, 2012). It consists of 29 questions for assessing risk of bias and precision of any observational study looking at an intervention or exposure (Viswanathan and Berkman, 2012). As such, the authors suggest it can be used for cohort, case-control, cross-sectional and case-series designs (Viswanathan and Berkman, 2012). As evidence of the lack of consensus on tools in this field, when developing the tool the authors assessed 1492 items from the published literature, selecting 60 of these for formal assessment before deciding on their 29 questions (Viswanathan and Berkman, 2012). These authors have evaluated the performance of RTI item bank compared with the NOS, concluding that the latter was easier to use, but RTI was considered to provide a more thorough quality assessment (Margulis *et al*., 2014). No independent external validation studies were identified.

### *2.3.8 Conclusions*

From the literature review conducted it was evident that there remains a lack of consensus on how to approach assessing the methodological quality of non-randomised and observational studies. Nevertheless, this remains an active area of research interest, particularly among those who seek to use the evidence generated in non-randomised studies to inform the development of Cochrane reviews and of health and social care policy. The Enhancing QUAlity and Transparency Of health Research (EQUATOR) Network provides useful resources for researchers to help promote improvement in the quality of reporting of health research (EQUATOR Network). It provides a contemporaneous repository of tools and checklists for researchers to use when planning, conducting and disseminating research findings (EQUATOR Network).

## 2.4 SELECTING A TOOL TO USE

After consideration of the tools available, RoBANS was selected for use in the systematic review (Chapter Three) because it incorporated evaluation of the important potential areas of bias and allowed for a simple evaluation of each element as high, low or unclear. This evaluation could then be described narratively and also presented in simple colour-coded graphical and tabular formats. Simple guidance was developed for those performing double data extraction to help support consistency of approach to assessing risk of bias, providing examples specific to the topic of the review (Appendix 3.3). RoBANS was modified for use in the review, omitting the evaluation of 'blinding of outcome assessment'. This decision reflects the fact that care home admission was not considered to be a subjective outcome and was typically being assessed on case note review.

## 2.5 INTEGRATING QUALITY ASSESSMENT WITH REVIEW FINDINGS

Having planned a robust evaluation of the methodological quality of the included studies in the review, the next challenge was to ensure that the findings of this quality assessment were presented with the narrative and numerical findings, so the results could be interpreted in their correct context. For the numerical results in particular, it was important that any effect sizes were presented with an evaluation of the quality of data from which they had been determined. The Grading of Recommendations Assessment Development and Evaluation (GRADE) approach offered the opportunity to do this. GRADE has been widely adopted by Cochrane, the World Health Organization and other healthcare organisations and journals (Guyatt *et al*., 2008).

GRADE incorporates the risk of bias assessment findings with an evaluation of consistency, indirectness, imprecision and publication bias, the factors which are recognised to lower the quality of a body of evidence (GRADE Working Group, 2004).

- *Consistency* indicates whether the findings are consistent with those in the other included studies.
- *Indirectness* indicates whether the evidence is applicable to the entire population or whether it is indirect and only applicable to a sub-set.
- *Imprecision* indicates the confidence interval associated with a finding, this will largely be reduced by studies with larger sample sizes, although not if the studies produce conflicting results.
- *Publication bias* can occur if not all studies conducted in the field are published and available for inclusion. Typically this occurs when studies with a negative result are not published, leading to a summary estimate of positive results which may be biased in this direction. This is more common in studies of interventions and can only be assessed formally where data are available for direct comparisons between studies.

Assessment of these parameters allows results to be described as high, moderate, low or very low quality, with an explanation of why evidence has been down- or upgraded. Factors which may increase the quality of evidence would be if there is: a large effect size; or when accounting for all potential confounding variables reduces the effect size or; if there is evidence of a dose-response relationship (Schunemann *et al*., 2011).

GRADE can be applied by individuals using their judgement to evaluate the factors which can decrease or increase the quality of the evidence reviewed. Alternatively, GRADEpro software is freely available (McMaster University and Evidence Prime Inc., 2015) for use by reviewers, allowing a systematic application of the guidance.

This Chapter has outlined the complexity of quality assessment for systematic reviews incorporating observational and non-randomised studies. It presents the rationale for the chosen approach in the systematic review, presented in Chapter Three and explains how the quality of the overall evidence will be described, to allow its incorporation into the overall review findings.

# CHAPTER THREE

# Predicting discharge to care homes from the hospital setting: A systematic review & meta-analysis

## 3.1 INTRODUCTION

Chapter One, Section 1.8 has demonstrated the gap in knowledge around the topic of new institutionalisation following hospital admission and the rationale for improving understanding of this issue. Although there have been systematic reviews to identify longitudinal predictors among community-dwelling older adults (Luppa *et al*., 2010) and those with dementia (Luppa *et al*., 2008, Toot *et al*., 2017), predictors from inpatient settings have not been reviewed.

The aim of this Chapter is to systematically review the published research to establish predictive factors for institutional care admission at time of discharge following unscheduled admission to the inpatient hospital setting. The review was conducted in two stages: first evaluating studies from the acute hospital setting and then evaluating those conducted in rehabilitation hospital settings.

The findings of two populations included in the review, studies set in the acute general hospital (Harrison *et al*., 2017c) and studies of stroke patients (Burton *et al*., 2018), have been published separately.

## 3.2 METHODS

### *3.2.1 Protocol and registration*

A protocol for the review was developed and PROSPERO Registration was granted on 20 August 2015 (CRD42015023497; available from: http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42015023497).

### *3.2.2 Eligibility criteria*

Studies were eligible for inclusion if they included adult participants who had an unscheduled hospital admission, excluding both those who were already resident in a care home before their hospital admission and studies reporting outcomes for those who were admitted to hospital electively.

The exposure of interest was any predictive factor for care home admission, with associated risk ratios or other statistical tests of association. The timing of the factor (e.g. differentiating characteristics present on admission from those which develop during the admission itself) was recorded.

Observational study designs, particularly cohort studies, cross-sectional studies and case-control studies were identified. Intervention studies seeking to alter rates of care home admission were excluded, as the outcome under study was the natural distribution of such predictive characteristics in the general population.

The outcome of interest was admission directly to a care home setting as new place of residence at the time of hospital discharge. A care home was defined in an inclusive way, recognising the international heterogeneity in terminology (Sanford *et al*., 2015). Residential and nursing home provision, long-term care and residential aged-care facilities were included where it was anticipated that the individual would remain resident in that setting.

Other exclusions were studies reporting on those admitted to care homes from community settings, or who were admitted to a care home at an interval period following hospital admission (i.e. they were discharged home initially and subsequently admitted to a care home), or where care home admission was only assessed at a fixed time point (e.g. six months).

No restrictions were made at the time of searching on date or language of publication. Authors and titles of conference abstracts were searched to identify subsequent full-text publications and these were included if found. Authors of abstracts were contacted to clarify if any subsequent publication occurred to facilitate inclusion. Systematic reviews were not included in the current review, but were included at the title and abstract screening stage so the full text could be identified, facilitating additional reference list searching to ensure inclusion of any other relevant articles.

### *3.2.3 Information sources*

The following databases were searched on 28 September 2015: Ovid MEDLINE (R) In Process and Other Non-Indexed Citations and Ovid MEDLINE (R) 1946 to present; Ovid EMBASE 1980 to 2015 Week 39 and EBSCOhost CINAHL Plus.

### *3.2.4 Search*

The search was developed in conjunction with an Information Specialist. Three key concepts were identified: care home admission, hospitalisation and risk or predictive factors. Results from a scoping review conducted in 2014 were used to identify relevant Medical Subject Headings (MeSH) terms and keywords (Armstrong *et al*., 2014).

Multiple iterations were made to create a search which was sufficiently sensitive to include relevant articles, but specific enough to limit the items returned. The full search strategy is included in Appendix 3.1. This was supplemented by reading the reference lists from systematic reviews to identify papers not found in the database search itself and assessment of any studies identified in the 2014 search which were not returned by the most recent search.

### *3.2.5 Study selection*

All titles and abstracts were screened electronically independently by two reviewers using Covidence software (Covidence, 2015). Conflicts were resolved by further review, discussing with a third reviewer as required. An inclusive approach was taken at this stage, with abstracts deemed potentially of use highlighted for full-text review.

Duplicate records were removed and systematic reviews were excluded and stored for reference list searching. Full-text review was undertaken in two phases, with two reviewers independently evaluating papers and applying the inclusion and exclusion criteria. Papers in the acute hospital setting were considered first and those in rehabilitation settings were evaluated later. Conflicts were resolved by consensus discussion.

### *3.2.6 Data collection*

A data extraction form (Appendix 3.2) was developed and piloted to improve usability. Data extraction was performed by a single reviewer, with three other reviewers performing double-extraction on a random sample of 25% of all included studies to ensure consistency of extraction and quality assessment.

### *3.2.7 Data items*

Data were extracted on: sample size, country, study design, prospective/retrospective, data collection period (dates and duration), acute hospital or rehabilitation setting, clinical setting, whether the paper was disease- or condition-specific and if so which disease or condition was reported. Data on the study population were extracted: age (with statistics as reported); proportion male sex; proportion of those surviving to discharge to who were newly discharged to a care home; type of care home; definition of care home; dementia diagnosis; and other comorbidities. The purpose of the original study was also recorded. Data were extracted to facilitate risk of bias assessment (discussed in Section 3.2.8). Possible predictors included: age, sex, living alone, patient wishes, family wishes, cognitive impairment, dementia, delirium, nutrition, mobility, functional ability, continence, polypharmacy, admission diagnosis, comorbidities, length of admission, recurrent previous admissions, prior care and end-of-life care. Additional space was included to record other predictive variables and any other relevant data identified by the assessor.

### *3.2.8 Risk of bias assessment in individual studies*

Risk of bias assessment was performed based on the Risk of Bias Assessment Tool for Non-Randomized Studies (RoBANS) (Kim *et al.*, 2013). This includes assessment of: selection of participants; confounding variables; measurement of exposure; incomplete outcome data and selective outcome reporting. The category 'blinding of outcome assessment' was omitted as it was determined that this was not a concern when considering the binary outcome of care home admission or not. All studies were assessed for the five included domains of RoBANS, assessing if the methods were of low, high or unclear risk for each of the forms of bias (selection, attrition, performance or reporting bias). Review-specific guidance (Appendix 3.3) was provided to assessors to facilitate a consistent approach to quality assessment.

### *3.2.9 Summary measures*

Studies were included if they reported quantitative data with associated statistical tests of association. These included reporting of risk ratios (RRs), odds ratios (ORs), correlations and differences in proportion between two groups with comparative significance testing.

### *3.2.10 Synthesis of results*

Quantitative analysis was performed using Comprehensive Meta-Analysis software version 2.0 (Borenstein *et al*., 2004). Where data were reported on the same predictor variable from three or more studies in similar populations, these were combined using a Random Effects model, to calculate a pooled odds ratio and 95% confidence interval. These data were evaluated using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) approach to describe the quality of the evidence (Guyatt *et al*., 2008). As the question of interest was to determine factors associated with care home admission, a question which can be explored using observational data, the quality of the evidence was not downgraded due to observational study design, but for the other recognised parameters which reduce the quality of the body of evidence on a topic, including risk of bias, heterogeneity and inconsistency (Guyatt *et al*., 2008). Statistical heterogeneity was quantified using $I^2$ and supplemented by evaluation of the clinical heterogeneity and inspection of forest plots. If more than ten studies evaluating the same predictor were identified (Sterne *et al*., 2011), it was planned to review funnel plots to evaluate the potential for publication bias.

### *3.2.11 Risk of bias across studies*

Risk of bias summary diagrams were created using Review Manager software version 5.3 (Cochrane Informatics & Knowledge Management Department, 2014) to allow a visualisation of the included studies. A narrative summary is provided highlighting common areas of concern. A risk of bias table is also provided (Appendix 3.4), with the details of the assessment made for each included study and justification of the decision.

### *3.2.12 Additional analyses*

Planned sub-group analyses were conducted where data were available evaluating: disease subgroups (e.g. stroke, fractured neck of femur, geriatric medicine); residential *vs* nursing care; country of origin; age <65 *vs* ≥65; timing of assessment (i.e. factors present prior to admission *vs* those related to events during hospitalisation); presence of dementia and presence of delirium.

## 3.3 RESULTS

### *3.3.1 Study selection*

The initial search identified 9,178 records after initial de-duplication. 22 papers were identified from the previous scoping review and from reference lists of systematic reviews. Following title and abstract screening, 434 records remained for full-text review. 381 records were excluded and a total of 53 studies were retained for inclusion in the review (Ackroyd-Stolarz *et al*., 2009, Adamis *et al*., 2006, Aitken *et al*., 2010, Alarcón *et al*., 1999, Astell *et al*., 2008, Basic and Shanley, 2015, Baztán *et al*., 2004, Béjot *et al*., 2012, Bogan *et al*., 2014, Bonnefoy *et al*., 1998, Bourdel-Marchasson *et al*., 2004, Brosseau *et al*., 1996, Brown *et al*., 2012, Cabré and Serra-Prat, 2004, Corsinovi *et al*., 2009, Gordon and Rosenthal, 1995, Haley *et al*., 2014, Ifejika *et al*., 2015, Inouye *et al*., 1998, Isaia *et al*., 2010, Jónsson *et al*., 2008, Jupp *et al*., 2011, Kammersgaard *et al*., 2001, Koyama *et al*., 2011, Kozyrskyi *et al*., 2005, Kwan and Hand, 2007, Lai *et al*., 1998, Lindenberg *et al*., 2014, Luk *et al*., 2009, Marengoni *et al*., 2008, McManus *et al*., 2009, Murie-Fernández *et al*., 2012, Murray *et al*., 2007, Neuhaus *et al*., 2014, Panella *et al*., 2012, Pautex *et al*., 2005, Pinedo *et al*., 2014, Portelli *et al*., 2005, Ramirez-Moreno *et al*., 2008, Romero-Ortuno *et al*., 2014, Rundek *et al*., 1998, Sacks *et al*., 2011, Schlegel *et al*., 2003, Smith and Stevens, 2009, Sood *et al*., 2011, Tamler and Perrin, 1992, Torpilliesi *et al*., 2010, Treger *et al*., 2008, Turco *et al*., 2013, Uthamalingam *et al*., 2011, Van Nes *et al*., 2001, Wong *et al*., 2010, Zureik *et al*., 1995)(**Figure 3.1**).

### *3.3.2 Excluded studies*

Studies were excluded for the following reasons: paper not about predictors of care home admission (n=94); composite outcome measure (e.g. care home admission and death) (n=59); not all admitted directly to a care home at time of hospital discharge (e.g. evaluated at fixed follow-up period such as six months) (n=54); not all hospital inpatients (n=42); duplicates (n=32); wrong study design (e.g. part of intervention study) (n=32); no numerical predictor data reported (n=25); elective admissions (n=11); insufficient information to evaluate not based on language (n=11); predictive analysis included those already resident in care homes (n=11); abstract identified and no full text available (n=6) and abstract identified but full text already in search (n=4).

### *3.3.3 Included study characteristics*

A summary of the characteristics of the included studies is provided in **Table 3.1**. The total review population of 53 studies included 1,457,881 participants. The sample size varied significantly from 79 – 948,880 participants (median sample size 536 participants; Inter-quartile range [IQR] 1,033). 55% of the studies were conducted in Europe and a third were from North America. Forty-three of the included studies were of cohort design, with five registry studies, two case-control studies, two audits and one survey. 59% were prospective in their design. Study duration was highly varied, with observational data ranging from 2 months to 10 years (median duration 19 months; IQR 39 months).

Three of the included studies were not available in English and were translated from the Spanish text (Baztán *et al*., 2004, Cabré and Serra-Prat, 2004, Ramirez-Moreno *et al*., 2008).

**Figure 3.1: PRISMA flow diagram**

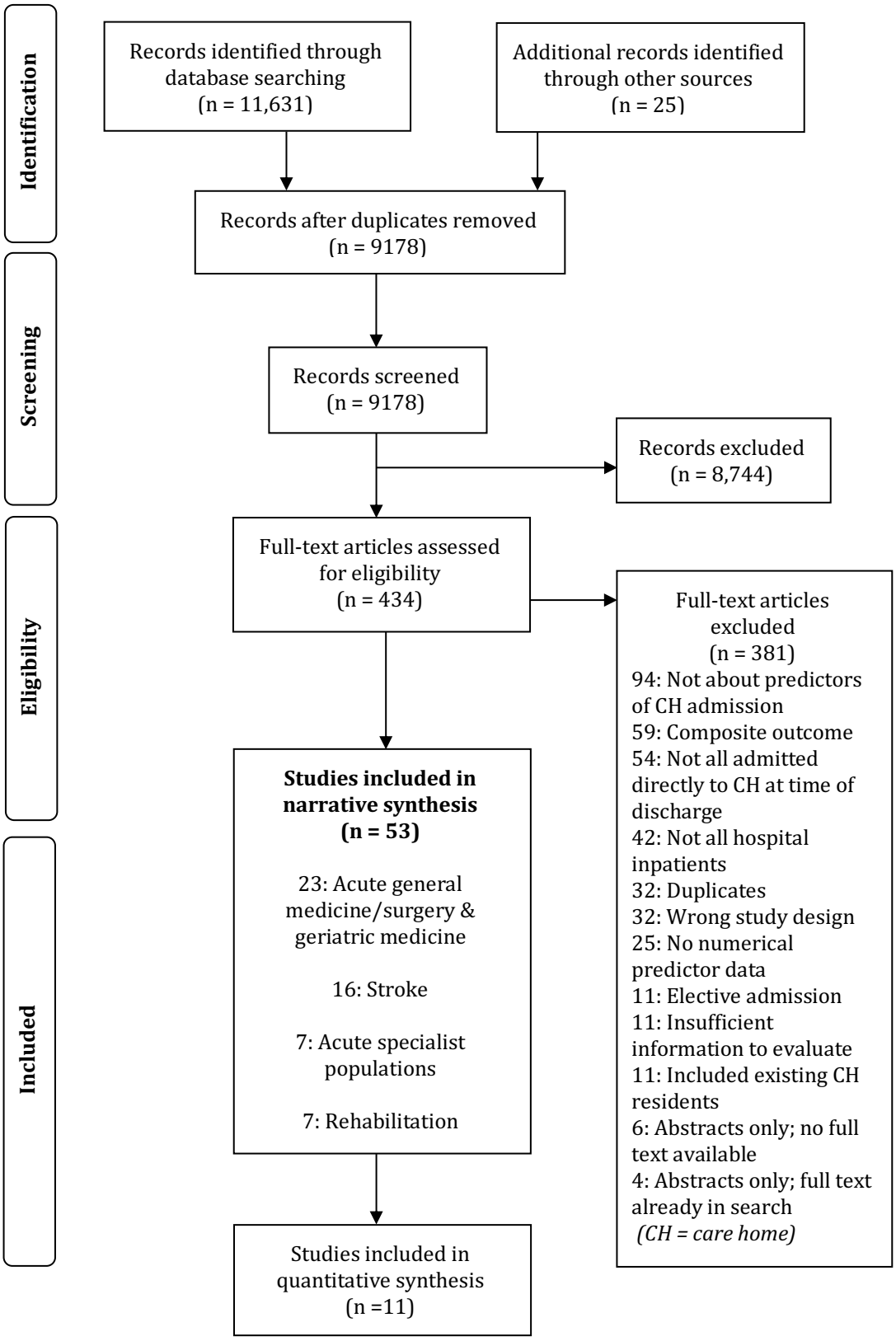


**Table 3.1: Summary characteristics of included studies**

| Study ID/Year | N | Country | Study design | Design | Duration | Setting |
|---|---|---|---|---|---|---|
| ***Acute general setting studies*** | | | | | | |
| Ackroyd-Stolarz 2009 | 982 | Canada | Retrospective | Cohort study using administrative data | 9 months | Acute inpatients >65 years who had no acute admissions or ED attendances in preceding six months |
| Adamis 2006 | 94 | UK | Prospective | Cohort study | 3 months | Acute admissions to elderly care unit (≥70 years) |
| Alarcón 1999 | 353 | Spain | Prospective | Cohort study | 10 months | Acute geriatric ward admissions |
| Astell 2008 | 234 | UK | Prospective | Cohort study | 48 months | Joint geriatric medicine/old age psychiatry unit |
| Basic 2015 | 2,125 | Australia | Prospective | Cohort study | 42 months | Tertiary referral hospital; admitted under a geriatrician |
| Baztán 2004 | 459 | Spain | Prospective | Cohort study | 19 months | Consecutive admissions with functional disability to a geriatric unit |
| Bonneyfoy 1998 | 1,066 | France | Prospective | Cohort study | 26 months | Admissions to acute geriatrics unit |
| Bourdel-Marchasson 2004 | 427 | France | Prospective | Cohort study | 12 months | Admissions to acute care geriatric unit |
| Brown 2012 | 392 | UK | Prospective | Cohort study | 6 months | Admission to acute care geriatric ward |
| Cabré 2004 | 585 | Spain | Prospective | Cohort study | 28 months | Admissions to an acute geriatric unit |
| Corsinovi 2009 | 620 | Italy | Prospective | Cohort study | 16 months | Admission to geriatric acute care ward |
| Gordon 1995 | 40,820 | USA | Retrospective | Cohort study | 40 months | Consecutive discharges from medicine & surgery |
| Inouye 1998 | 727 | USA | Prospective | Cohort study | 5-8 months | Three university affiliated teaching hospitals; admissions of older adults |
| Isaia 2010 | 123 | Italy | Prospective | Cohort study | 8 months | Admission to the department of geriatric medicine in university hospital |
| Jónsson 2008 | 749 | Nordic countries | Prospective | Cohort study | 15 months | Adults ≥75 years admitted to acute medical care |
| Kozyrskyj 2005 | 17,984 | Canada | Retrospective | Cohort study | 84 months | Older adults in medicine and surgery with long-stay (>30 days) admission |
| Luk 2009 | 535 | Hong Kong | Retrospective | Cohort study | 27 months | Admissions to geriatric units |
| Marengoni 2008 | 830 | Italy | Prospective | Cohort study | 22 months | Consecutive admissions to acute care geriatrics |

*Table 3.1 continued overleaf*

*Table 3.1 continued*

| Study ID/Year | N | Country | Study design | Design | Duration | Setting |
|---|---|---|---|---|---|---|
| ***Acute general setting studies (continued)*** | | | | | | |
| Romero-Ortuno 2014 | 15,873 | Ireland | Retrospective | Hospital-based registry | 120 months | Medical admissions aged ≥65 years |
| Smith 2009 | 6,006 | USA | Retrospective | Cohort study | 12 months | Discharges from those aged ≥60 years admitted to S&W Healthcare in Temple |
| Van Nes 2001 | 1,145 | Switzerland | Prospective | Cohort study | 24 months | Convenience sample of patients admitted to geriatric medicine hospital |
| Wong 2010 | 262,439 | The Netherlands | Retrospective | Cohort study | 12 months | Individuals aged ≥65 years, admitted to hospital not utilising any kind of formal care |
| ***Stroke studies*** | | | | | | |
| Béjot 2012 | 1,069 | France | Prospective | Population registry | 48 months | Admissions with diagnosis of stroke |
| Brosseau 1996 | 152 | Canada | Prospective | Cohort study | 15 months | Consecutive stroke admissions to the physical rehabilitation department of a general hospital |
| Ifejika 2015 | 346 | USA | Retrospective | Registry | 34 months | Admissions to university stroke & neurorehabilitation service |
| Kammersgaard 2001 | 1,156 | Denmark | Prospective | Cohort study | NR | Consecutive acute stroke admissions to an in-patient neurology department |
| Koyama 2011 | 163 | Japan | Prospective | Cohort study | 18 months | First ever stroke admissions to a rehabilitation hospital |
| Kwan 2007 | 439 | UK | Prospective | Cohort study | 10 months | Consecutive admissions to university hospital with suspected stroke |
| Lai 1998 | 662 | USA | Prospective | Cohort study | 24 months | Admissions for acute stroke to eight acute care hospitals |
| McManus 2009 | 82 | UK | Prospective | Cohort study | 7 months | Consecutive admissions to specialist stroke unit |
| Murie-Fernández 2012 | 536 | Canada | Retrospective | Cohort study | 44 months | Stroke admissions to the neurorehabilitation facility of a university hospital |
| Pinedo 2014 | 241 | Spain | Prospective | Cohort study | 8 months | Admissions to rehabilitation unit after stroke of two university hospitals |
| Portelli 2005 | 2,778 | UK | Retrospective | Audit | 2 months | Consecutive admissions with stroke to 79 hospitals |

*Table 3.1 continued overleaf*

***Table 3.1 continued***

| Study ID/Year | N | Country | Study design | Design | Duration | Setting |
|---|---|---|---|---|---|---|
| ***Stroke studies (continued)*** | | | | | | |
| Ramirez-Moreno 2008 | 130 | Spain | Retrospective | Hospital registry | 26 months | Consecutive stroke admissions to the neurology unit and other ward services |
| Rundek 1998 | 573 | USA | Prospective | Cohort study | 77 months | Admissions with first ischaemic stroke |
| Schlegel 2003 | 94 | USA | Retrospective | Cohort study | 4 months | Stroke unit admissions in a university hospital |
| Treger 2008 | 1,583 | Israel | Prospective | National survey | 2 months | Acute stroke patients hospitalised in 28 medical centres |
| Turco 2013 | 176 | Italy | Retrospective | Cohort study | 47 months | Admissions to department of rehabilitation and aged care after stroke |
| ***Acute specialist population studies*** | | | | | | |
| Aitken 2010 | 6,069 | Australia | Retrospective | Secondary analysis of registry data | 48 months | 15 regional and tertiary hospitals; admissions >24hrs for acute treatment of injury |
| Bogan 2014 | 364 | USA | Retrospective | Case-control study | 12 months | Admissions to tertiary referral hospital |
| Murray 2007 | 86 | Australia | Retrospective | Case-control study | 72 months | Hospital inpatients >75 years who sustained proximal femoral fractures during admission |
| Neuhaus 2014 | 132,005 | USA | Retrospective | Cohort study using national data | 48 months | Admissions with an isolated acute proximal humerus fracture |
| Sacks 2011 | 948,880 | USA | Retrospective | Cohort study using national data | 48 months | Admissions to trauma centres |
| Sood 2011 | 1,286 | Canada | Retrospective | Cohort study | 84 months | Hospitalised dialysis patients who had functional status assessed within 24hrs of admission |
| Uthamalingam 2011 | 883 | USA | Retrospective | Cohort study | 48 months | Consecutive admissions with acute decompensated heart failure |

*Table 3.1 continued overleaf*

***Table 3.1 continued***

| Study ID/Year | N | Country | Study design | Design | Duration | Setting |
|---|---|---|---|---|---|---|
| ***Rehabilitation setting studies*** | | | | | | |
| Haley 2014 | 86 | Australia | Prospective | Cohort study | 6 months | Subacute aged care admissions to a rehabilitation hospital |
| Jupp 2011 | 200 | UK | Prospective | Cohort study | NR | Admissions to two non-acute geriatric rehabilitation wards |
| Lindenberg 2014 | 248 | Australia | Retrospective | Audit | 19 months | Admissions to a geriatric rehabilitation facility |
| Panella 2012 | 104 | Italy | Prospective | Cohort study | NR | Admissions to a rehabilitation ward of a district hospital |
| Pautex 2005 | 86 | Switzerland | Prospective | Cohort study | 17 months | Hip fracture admissions to a rehabilitation ward in a geriatric hospital |
| Tamler 1992 | 79 | USA | Prospective | Cohort study | 8 months | Admissions to rehabilitation unit in a community hospital |
| Torpilliesi 2010 | 2,340 | Italy | Retrospective | Cohort study | 48 months | Consecutive admissions to rehabilitation and aged care unit |

***Notes**: ED – emergency department; NR – not reported*

Data are reported primarily by setting, rather than by disease sub-group, based on the available data. The acute general settings were the largest group (**Table 3.2**) with a further 16 in stroke populations (**Table 3.3**), seven studies featured a specialist population in the acute hospital (**Table 3.4**) and seven were in rehabilitation settings (**Table 3.5**).

Four studies had a mean age which was <65 years (Bogan *et al*., 2014, Sacks *et al*., 2011, Gordon and Rosenthal, 1995, Schlegel *et al*., 2003) and the average age of participants was not reported in a further five studies (Smith and Stevens, 2009, Astell *et al*., 2008, Corsinovi *et al*., 2009, Kozyrskyi *et al*., 2005, Sood *et al*., 2011).

The proportion of included participants who were discharged to a care home varied across the included studies from 3% to 77% (median 16%, IQR 18). In five studies it was not possible to calculate the proportion discharged to a care home (Corsinovi *et al*., 2009, Romero-Ortuno *et al*., 2014, Isaia *et al*., 2010, Bogan *et al*., 2014, Ramirez-Moreno *et al*., 2008). The absolute number of participants discharged to a care home was 15,052 out of 330,232 surviving to discharge, using data from 39 of the included studies, as this level of detail was not provided in the other 14.

Twenty-six (49%) of the included studies evaluated participants for cognitive impairment or dementia. They varied in presenting average cognitive test scores or proportions with dementia. Thirty-four (64%) of the included studies reported other baseline comorbidities

There was significant heterogeneity in terminology used to describe the care home setting: 21 studies identified participants being admitted to nursing homes and three to nursing or residential homes. Long-term care was used in eight cases; institution or institutionalisation in ten cases and the term ‘care home’ was only used in one of the studies. Only two studies provided a definition of what they considered the setting to comprise (Sood *et al*., 2011, Ifejika *et al*., 2015). For consistency, the term ‘admission to care home’ will be used when describing the reported associations between predictors and this outcome.

**Table 3.2: Characteristics of participants from studies in the acute general hospital setting**

| Study ID | Mean Age (SD) | Male sex % | Inpatient death N (%) | Discharged to CH% (N/total) | Dementia & cognitive impairment | Other comorbidities |
|---|---|---|---|---|---|---|
| Ackroyd-Stolarz 2009 | 78 (8) | 48 | 136 (14) | 3 (29/846) | NR | NR |
| Adamis 2006 | 83.8 (6.5) | 40 | 9 (10) | 20 (17/85) | NR | NR |
| Alarcón 1999 | 81.8 (7.2) | 34 | 37 (11) | 3 (10/316) | NR | NR |
| Astell 2008 | NR | 44 | 55 (24) | 77 (127/179) | 38% severe; 41.5% moderate; 20.5% mild (using MMSE) | Number of physical complaints reported; 12% had >6 |
| Basic 2015 | 83.0 (7.9) Dev<br>82.7 (7.5) Val | 42 Dev<br>40 Val | (10) Dev<br>(10) Val | 6 (values NR) | 41% Dev<br>44% Val | Data on delirium, BPSD, acute renal failure and other comorbidities |
| Baztán 2004 | 80.56 (7.45) | 35 | NR | 16% (values NR) | 27% scored ≥5 on SPMSQ | Data reported in Charlson Index at baseline |
| Bonneyfoy 1998 | 82.7 (6.6) | 31 | 84 (8) | 61 (595/982) | 53% 'Abnormal mental status' | Defined by ICD-9 characteristics |
| Bourdel-Marchasson 2004 | 85.6 (6.8) Ins<br>84.6 (6.2) Com | 26 Ins<br>52 Com | Excluded | 27 (117/427) | 48% community; 61% institution (cognitive impairment) | Charlson index reported for each group |
| Brown 2012 | 83.2 (5.5) | 72 | 33 (8) | 11 (38/359) | Mean AMT 8.1 (3.2) score | Mean number 3.8 (1.8) |
| Cabré 2004 | 84 (6.2) | 46 | 26 (4) | 16 (90/559) | 15% who went home<br>30% who were institutionalised | Data reported on proportion in each group with categories of comorbidities |
| Corsinovi 2009 | NR | NR | NR | NR | NR | NR |
| Gordon 1995 | 55 (22) Unmarried<br>58 (16) Married | 46 | 1647 (4) | 4 (1,631/39,173) | NR | Admission severity of illness score |
| Inouye 1998 | 78.9 (6.9) | 40 | 35 (5) | 9 (60/692) | 19% | Primary medical problem reported |
| Isaia 2010 | 82.2 (7.3) | 33 | 14 (5) | NR | Mean MMSE 23.9 (8.1) | Data on APACHE II and GDS reported |

*Table 3.2 continued overleaf*

***Table 3.2 continued***

| Study ID | Mean Age (SD) | Male sex % | Inpatient death N (%) | Discharged to CH % (N/total) | Dementia & cognitive impairment | Other comorbidities |
|---|---|---|---|---|---|---|
| Jónsson 2008 | 83.7 (5.4) | 34 | 42 (6) | 12 (81/707) | 18% Mod/severe cognitive decline | Data on number of diagnoses |
| Kozyrskyj 2005 | NR | NR | (22) | 19 (values NR) | NR | NR |
| Luk 2009 | 80.6 (6.89) | 43 | NR | 22 (116/535) | Mean MMSE 17.1 (6.3) | NR |
| Marengoni 2008 | 78.5 (7.2) | 50 | 64 (7) | 3 (23/830) | 39% (MMSE <24) | Data on diseases and disorders on admission reported |
| Romero-Ortuno 2014 | 76.3 (7.3) ND<br>77.4 (7.5) 1-2 D<br>79.3 (7.6) 3-5 D<br>80.9 (7.6) ≥6 D | NR | NR | NR | NR | NR |
| Smith 2009 | NR | 50 | NR | 16 (981/6,006) | NR | NR |
| Van Nes 2001 | 84.1 (6.7) | 30 | 80 (7) | 13 (147/1,145) | NR | NR |
| Wong 2010 | 74.2 (6.4) | 50 | NR | 3 (9,049/262,439) | 0.40% | Data on comorbidities reported |

***Notes:*** *APACHE II – Acute Physiology and Chronic Health Evaluation; CH – Care Home; Cog Imp – cognitive impairment; Com – community; D – deficits; Dev – development cohort; GDS – Geriatric Depression Scale; ICD-9 – international classification of diseases version 9; Ins – institutional care; MMSE – mini mental state examination; ND – no deficits;*
*SPMSQ - Short Portable Mental Status Questionnaire*; *Val – validation cohort. All percentages rounded to nearest whole number.*

**Table 3.3: Characteristics of participants from studies in stroke care settings**

| Study ID | Mean Age (SD) | Male sex % | Inpatient death N (%) | Discharged to CH % (N/total) | Dementia & cognitive impairment % | Other comorbidities |
|---|---|---|---|---|---|---|
| Béjot 2012 | H 71.6 (16.3)<br>R 72.7 (15.4)<br>NH 85.3 (7.5) | 46% | 156 (15) | 15% (140/913) | 19% (171/913) | Significant medical comorbidities reported |
| Brosseau 1996 | 68.9 (14.1) | 50% | NR | 23% (35/152) | NR | NR |
| Ifejika 2015 | C 58.9 (13.8)<br>SNF 68.2 (12.2) | C 57%;<br>SNF 60% | NR | 14% (47/346) | NR | NR |
| Kammersgaard 2001 | Inf 77.4 (8.6)<br>N Inf 73.4 (11.3) | 46% | 236 (20) | 26% (236/920) | NR | Data on vascular comorbidities reported |
| Koyama 2011 | 69.71 (12) | 61% | NR | 25% (40/163) | NR | NR |
| Kwan 2007 | Inf 77.9 (10.8)<br>N Inf 73.2 (12.6) | 49% | 54 (12) | 39% (150/381) | NR | Data on vascular risk factors reported |
| Lai 1998 | NH 80.9 (8.6)<br>RF 70.6 (9.9)<br>H 69.6 (10.5) | 50% | 22 (3) | 19% (128/660) | NR | Data on vascular risk factors reported |
| McManus 2009 | 66.4 (15.9) | 62% | 8 (10) | 14% (10/74) | IQCODE >3 28% | Data on vascular and delirium risk factors reported |
| Murie-Fernández 2012 | 69 (15) | NR | NR | 28%* | NR | NR |
| Pinedo 2014 | 71.5 (11.8) | 57% | NR | 19% | Mean SPMSQ 3.0 (2.8) | Charlson Index reported on admission |
| Portelli 2005 | NR | NR | 812 (29) | 14% | NR | Data on previous stroke only |

*Table 3.3 continued overleaf*

***Table 3.3 continued***

| Study ID | Mean Age (SD) | Male sex % | Inpatient death N (%) | Discharged to CH % (N/total) | Dementia & cognitive impairment % | Other comorbidities |
|---|---|---|---|---|---|---|
| Ramirez-Moreno 2008 | NU 87.7 (3.1)<br>Other 88.9 (3.3) | NU 46%<br>Other 33% | NU (14)<br>Other (17) | NU 11%<br>Other 30% | NU 7%<br>Other 12% | Baseline comorbidities reported |
| Rundek 1998 | 69.9 (12.4) | 47% | 31 (5) | 9% (54/573) | NR | NR |
| Schlegel 2003 | 65 (15) | 49% | 12 (10) | 12% (11/94) | NR | NR |
| Treger 2008 | H 69 (12.5)<br>R 72.4 (11.5)<br>NH 80.1 (9.2) | 44% | 162 (8) | 7% (117/1583) | H 6.1%<br>R 5.6%<br>NH 28% | Baseline comorbidities reported |
| Turco 2013 | 81.7 (6.4) | 33% | 20 (11) | 27% (42/156) | Mean MMSE 18.1 (7.0) | Malnutrition and depression recorded at baseline |

***Notes:*** *C – community; H – home; Inf – infection; MMSE – mini-mental state examination; NH – nursing home; N Inf – no infection; NR – not reported; NU – neurology unit; R – rehab; RF – residential facility; SNF – skilled nursing facility; SPMSQ – short portable mental status questionnaire*

** Composite of institution & assisted living facility, individual data not reported. All percentages rounded to nearest whole number*

**Table 3.4: Characteristics of participants from studies of specialist populations in the acute general hospital**

| Study ID | Specialist population | Age<br>Mean (SD)<br>Median [IQR] | Male sex % | Inpatient death n (%) | Discharged to CH % (n/total) | Dementia diagnosis % | Other comorbidities (Y/N) |
|---|---|---|---|---|---|---|---|
| Aitken 2010 | Trauma | 78 [71-84] | 41 | 301 (5) | 5 (266/5768) | NR | NR |
| Bogan 2014 | Carbapenem-resistant *Enterobacteriaceae* | 62 (16) | 47 | 60 (17) | Unable to determine | NR | Charlson index reported |
| Murray 2007 | Inpatient femoral fractures | Hosp: 84 (4.2)<br>Comm: 84.1 (4.0) | 33 | 16 (19) | 27 (19/70) | NR | Mean comorbidities & Charlson index reported |
| Neuhaus 2014 | Isolated acute proximal humerus fractures | 79 (7.7) | 15 | (2) | 35 (values NR) | 4% | 76% 'comorbidities present' |
| Sacks 2011 | Trauma | 47.73 | 64 | 88240 (6) | 11 (values NR) | NR | NR |
| Sood 2011 | ESRF on dialysis | NR | 53 | 250 (19) | 7 (72/1036) | 2% | Other comorbid conditions reported |
| Uthamalingam 2011 | Heart failure | 79 (8) | 48 | 62 (7) | 24 (197/821) | 11% | Baseline comorbidities reported |

***Notes:*** *CH – care home; Comm – community; ESRF – end stage renal failure; Hosp – hospital. All percentages rounded to nearest whole number.*

**Table 3.5: Characteristics of participants from studies in rehabilitation hospital settings**

| Study ID | Disease-specific rehabilitation | Age Mean (SD) Median [IQR] | Male sex % | Inpatient death n (%) | Discharged to CH % (n/total) | Dementia diagnosis % | Other comorbidities (Y/N) |
|---|---|---|---|---|---|---|---|
| Haley 2014 | n/a | 81.3 (7.7) | 49 | 3 (3) | 57 (47/83) | NR | NR |
| Jupp 2011 | n/a | 80.9 (7.1) | 39 | NR | 27 (54/200) | 42% (83/200) impaired cognitive function* | Baseline characteristics including vision, gait, hearing and falls reported |
| Lindenberg 2014 | n/a | 79 (9) | 34 | NR | 12 (28/227) | NR | Stroke, other neurological conditions, debility %s |
| Panella 2012 | n/a | 71.4 (12.9) | 46 | NR | 4 (values NR) | NR | NR |
| Pautex 2005 | Hip fracture | 84.2 (6.8) | 22 | NR | 26 (21/80) | 44% MMSE <24 on admission | Depression assessed at baseline; no other comorbidities reported |
| Tamler 1992 | n/a | 59.9 (18.6) Home 72.2 (7.8) NH | 48 | NR | 8 (6/79) | NR | Admission diagnoses reported (predominantly neurological conditions) |
| Torpilliesi 2010 | Stroke | 81.7 (6.4) | 33 | 20 (11) | 27 (42/156) | Mean MMSE 18.1 (+/-7.0) | Malnutrition and depression recorded |

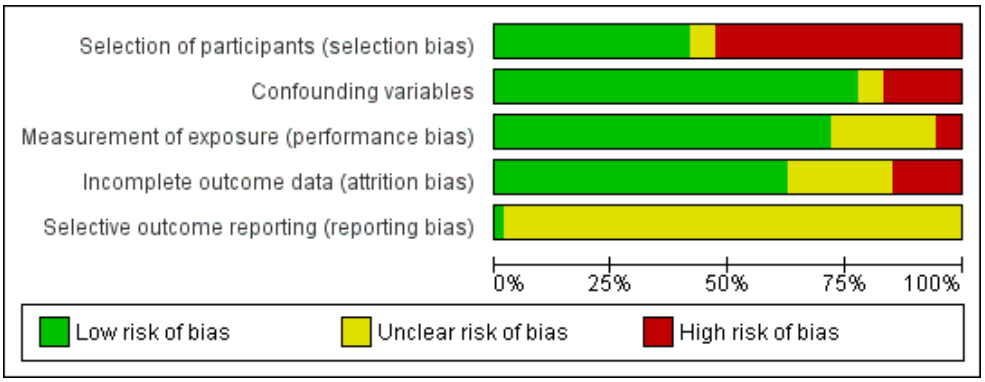
***Notes:*** *AMT – abbreviated mental test; MMSE – mini mental state examination; NR – not reported;*

** Impaired cognitive function defined as AMT <7/10 or <26/30 on MMSE. All percentages rounded to nearest whole number*

### *3.3.4 Risk of bias within studies*

The risk of bias assessment for all included studies is summarised graphically in **Figures 3.2** & **3.3** and described in full in Appendix 3.4.

**Figure 3.2: Risk of bias summary for all studies (n=53)**




*Created using Review Manager (Cochrane Informatics & Knowledge Management Department, 2014)*

#### 3.3.4.1 Selection of participants

Twenty-eight of the included studies (Ackroyd-Stolarz *et al.*, 2009, Baztán *et al.*, 2004, Bonnefoy *et al.*, 1998, Bourdel-Marchasson *et al.*, 2004, Brown *et al.*, 2012, Gordon and Rosenthal, 1995, Haley *et al.*, 2014, Isaia *et al.*, 2010, Jónsson *et al.*, 2008, Koyama *et al.*, 2011, Kozyrskyi *et al.*, 2005, Lai *et al.*, 1998, Lindenberg *et al.*, 2014, Luk *et al.*, 2009, Marengoni *et al.*, 2008, McManus *et al.*, 2009, Murray *et al.*, 2007, Pautex *et al.*, 2005, Pinedo *et al.*, 2014, Rundek *et al.*, 1998, Sacks *et al.*, 2011, Schlegel *et al.*, 2003, Smith and Stevens, 2009, Sood *et al.*, 2011, Treger *et al.*, 2008, Uthamalingam *et al.*, 2011, Wong *et al.*, 2010, Zureik *et al.*, 1995) were at high risk of selection bias and this was the most common issue identified in the risk of bias assessment. This judgement was made as studies often recruited non-consecutive samples, included only an incident diagnosis and used exclusion criteria likely to be significant in this population (e.g. excluded those with previous hospital admissions etc.). Three studies were at unclear risk of bias as no data were reported on those eligible for the study, but not recruited (Inouye *et al.*, 1998, Murie-Fernández *et al.*, 2012, Van Nes *et al.*, 2001).

#### 3.3.4.2 Confounding variables

Nine studies were considered at high risk of bias as they failed to take account of likely confounding variables in their analysis of predictors (Corsinovi *et al.*, 2009, Koyama *et al.*, 2011, McManus *et al.*, 2009, Murie-Fernández *et al.*, 2012, Murray *et al.*, 2007, Panella *et al.*, 2012, Portelli *et al.*, 2005, Ramirez-Moreno *et al.*, 2008, Van Nes *et al.*, 2001). For three studies, the risk was considered unclear, two reported they had performed logistic regression but did not report the variables included in their model (Astell *et al.*, 2008, Tamler and Perrin, 1992) and the third only adjusted for age (Romero-Ortuno *et al.*, 2014).

**Figure 3.3: Risk of bias summary chart**


*Created using Review Manager(Cochrane Informatics & Knowledge Management Department, 2014)*

#### 3.3.4.3 Measurement of exposure

Exposure in this context refers to the measurement of the predictor variables described in each study, e.g. delirium, medication use. Three studies were considered at high risk of bias with respect to measurement of exposure due to missing data for included participants on the exposure of interest (Portelli *et al*., 2005, Van Nes *et al*., 2001, Zureik *et al*., 1995). Twelve studies were considered of unclear risk as their study procedures for the collection or extraction of exposure data were not described fully (Adamis *et al*., 2006, Alarcón *et al*., 1999, Cabré and Serra-Prat, 2004, Koyama *et al*., 2011, Luk *et al*., 2009, McManus *et al*., 2009, Murie-Fernández *et al*., 2012, Neuhaus *et al*., 2014, Sacks *et al*., 2011, Smith and Stevens, 2009, Torpilliesi *et al*., 2010, Wong *et al*., 2010).

#### 3.3.4.4 Incomplete outcome data

Eight studies were considered at high risk of bias due to incomplete outcome data, where outcome data were incompletely ascertained without explanation of why they were missing (Aitken *et al*., 2010, Alarcón *et al*., 1999, Astell *et al*., 2008, Haley *et al*., 2014, Jónsson *et al*., 2008, Lai *et al*., 1998, Lindenberg *et al*., 2014, Portelli *et al*., 2005). Twelve studies were considered at unclear risk of bias most often because data were reported as proportions without providing the absolute values, so it was not possible to establish the completeness of outcome reporting (Basic and Shanley, 2015, Baztán *et al*., 2004, Bogan *et al*., 2014, Corsinovi *et al*., 2009, Isaia *et al*., 2010, Kozyrskyi *et al*., 2005, Murie-Fernández *et al*., 2012, Panella *et al*., 2012, Pinedo *et al*., 2014, Ramirez-Moreno *et al*., 2008, Romero-Ortuno *et al*., 2014, Sacks *et al*., 2011).

#### 3.3.4.5 Selective outcome reporting

Only one study was considered of low risk of bias, due to the prior publication of a study protocol outlining planned outcome assessment (Inouye *et al*., 1998). The other 52 studies were all rated as unclear for this domain.

### *3.3.5 Results of individual studies*

There was significant heterogeneity across all studies in their methods of analysis and extent of reporting methods for reporting predictors and analyses. Data are reported by study setting: acute general setting (23 studies, n=354,985 participants); stroke (16 studies, n=10,180 participants); acute specialist population (seven studies, n= 1,089,573 participants) and rehabilitation setting (seven studies, n= 3,143 participants).

#### 3.3.5.1 Acute general setting studies

Fourteen studies were set in geriatric medical units, six included medical and surgical admissions and three included only acute medical admissions. The majority (13/23) presented multivariate models with predictors, summarised in **Table 3.6**. Only seven of these also present all results, including those where no statistically significant association was identified (Zureik *et al*., 1995, Marengoni *et al*., 2008, Wong *et al*., 2010, Jónsson *et al*., 2008, Bourdel-Marchasson *et*

*al*., 2004, Baztán *et al*., 2004, Basic and Shanley, 2015). Taking account of the heterogeneity of measurement approaches, these studies identify an association between longer length of stay, functional impairment, cognitive impairment and falls, with the need for care home admission at discharge.

**Table 3.6: Multivariate predictors of care home admission from acute general settings**

| Study ID | Potential predictors evaluated | Statistically significant predictors | |
|---|---|---|---|
| | | **Predictor** | **Odds Ratio (OR) or Risk Ratio (RR) (95% Confidence Interval)** |
| Ackroyd-Stolarz 2009 | Age; Sex; Comorbidities; Length of stay<br>Other: Use of ventilator; Occurrence of an adverse event | Length of stay (days) | OR 1.04 (1.02-1.06) |
| Alarcón 1999 | Living alone; Cognitive impairment; Malnutrition; Functional ability; Polypharmacy<br>Other: Pressure sores; Presence of a pension; Family carer | Functional disability (measured using the Red Cross Functional Disability Scale >3) | OR 3.41 (1.46-5.00) |
| Basic 2015 | Age; Dementia; Delirium; Comorbidities<br>Other: Frailty; Urinary retention; Deconditioning | Dementia | D: OR 1.83 (1.00-3.37);<br>V: OR 2.06 (1.19-3.55) |
| | | Frailty | D: OR 2.08 (1.40-3.10)<br>V: OR 1.60 (1.14-2.24) |
| | | Urinary retention | D: OR 2.60 (1.23-5.47);<br>V: OR 3.30 (1.77-6.13) |
| | | Deconditioning | D: OR 2.93 (1.64-5.23);<br>V: OR 2.57 (1.53-4.32) |
| Baztán 2004 | Age; Sex; Cognitive impairment; Admission diagnosis; Functional status; Comorbidities<br>Other: Albumin; Sociofamiliar scale | Age (years) | OR 1.06 (1.01-1.12) |
| | | Admission diagnosis (orthopaedic *vs* not) | OR 1.06 (1.01-1.12) |
| | | Other (sociofamiliar scale ≥9) | OR 6.83 (1.91-24.47) |

*Table 3.6 continued overleaf*

***Table 3.6 continued***

| Study ID | Potential predictors evaluated | Statistically significant predictors | |
|---|---|---|---|
| | | **Predictor** | **Odds Ratio (OR) or Risk Ratio (RR) (95% Confidence Interval)** |
| Bourdel-Marchasson 2004 | Age; Sex; Delirium; Cognitive impairment; Malnutrition; Polypharmacy; Comorbidity; Function; Admission diagnosis<br>Other: Weight | Sex (female) | OR 2.15 (1.22-3.78) |
| | | Prevalent delirium (CAM) | OR 3.19 (1.33-7.64) |
| | | Malnutrition (low intake) | OR 2.5 (1.35-4.63) |
| | | Admission diagnosis: Falls<br>Stroke | OR 2.16 (1.22-3.84)<br>OR 2.03 (1.04-3.94) |
| Cabré 2004 | Age; Dementia; Delirium; Malnutrition; Mobility; Functional ability; Comorbidities; Incontinence<br>Other: Sleep disorder; Pressure ulcers; Falls | Function: Barthel Index (0-20 *vs* >60)<br>Barthel Index (21-40 *vs* >60) | OR 3.19 (1.34-7.58)<br>OR 3.6 (1.51-8.59) |
| | | Comorbidities: Cancer<br>Chronic lung disease | OR 0.28 (0.08-0.97)<br>OR 0.50 (0.29-0.89) |
| | | Other: Falls (in last year) | OR 2.99 (1.78 -5.00) |
| Jónsson 2008 | Age; Sex; Cognitive impairment; Functional ability; Prior care; Admission diagnoses<br>Other: Country | Cognitive impairment (moderate/severe on cognitive performance scale) | OR 8.63 (3.91-19.01) |
| | | Functional ability (Problems with IADLs) | OR 6.04 (1.35-27.12) |

*Table 3.6 continued overleaf*

***Table 3.6 continued***

| Study ID | Potential predictors evaluated | Statistically significant predictors | |
|---|---|---|---|
| | | **Predictor** | **Odds Ratio (OR) or Risk Ratio (RR) (95% Confidence Interval)** |
| Kozyrskyj 2005 | Living alone; Cognitive impairment; Admission diagnosis; Comorbidities; Length of admission; Prior care; Other: Income; In-hospital fall; Winnipeg resident; Surgical *vs* Medical; Geriatric unit; Dialysis; Rehabilitation; Discharge hospital; Year; Other diagnoses | Living alone: 65-74 only | OR 1.27 (1.08-1.48) |
| | | Cognitive impairment: 65-74<br>75-84<br>≥85 | OR 2.42 (1.65-3.56)<br>OR 2.75 (2.16-3.50)<br>OR 1.51 (1.20-1.90) |
| | | Admission diagnosis: Stroke 65-74<br>75-84<br>≥85 | OR 1.83 (1.33-2.53)<br>OR 1.93 (1.59-2.33)<br>OR 1.54 (1.29-1.86) |
| | | Admission diagnosis: Nervous system disorder: 65-74<br>75-84<br>≥85 | OR 2.08 (1.21-3.57)<br>OR 3.05 (2.08-4.46)<br>OR 1.72 (1.08-2.75) |
| | | Comorbidities (using Charlson Index):<br>65-74 Some<br>75-84 Multiple<br>≥85 Multiple | <br>OR 1.33 (1.04-1.69)<br>OR 0.73 (0.56-0.95)<br>OR 0.68 (0.49-0.94) |
| | | Length of admission (>120 days):<br>65-74<br>75-84<br>≥85 | <br>OR 6.65 (5.10-8.67)<br>OR 7.16 (6.05-8.46)<br>OR 2.05 (1.70-2.47) |
| | | Prior home care: 65-74<br>75-84<br>≥85 | OR 1.55 (1.31-1.83)<br>OR 1.48 (1.34-1.62)<br>OR 1.40 (1.27-1.54) |
| | | Lowest income: 75-84<br>≥85 | OR 1.18 (1.01-1.37)<br>OR 1.23 (1.07-1.42) |
| | | In-hospital Fall: 75-84<br>No fall: ≥85 | OR 1.25 (1.01-1.55)<br>OR 7.00 (5.78-8.48) |
| *Results presented stratified by age group: 65-74; 75-84; ≥85* | | | |

*Table 3.6 continued overleaf*

***Table 3.6 continued***

| Study ID | Potential predictors evaluated | Statistically significant predictors | |
|---|---|---|---|
| | | **Predictor** | **Odds Ratio (OR) or Risk Ratio (RR) (95% Confidence Interval)** |
| Luk 2009 | Age; Cognition; Mobility; Admission diagnosis; Functional status; Length of stay<br>Other: Pressure sores; Marital status; Albumin level | Cognitive performance (Higher C-MMSE) | OR 0.93 (0.87-0.98) |
| | | Urinary incontinence | OR 5.13 (2.66-10.6) |
| | | Mobility (Higher Elderly Mobility Scale) | OR 0.91 (0.84-0.97) |
| | | Admission diagnosis: Falls | OR 2.4 (1.03-5.57) |
| | | Marital status | OR 2.74 (1.36-5.53) |
| | | Albumin level (Higher; level not stated) | OR 0.93 (0.88-0.99) |
| Marengoni 2008 | Age; Sex; Cognitive impairment; Functional ability; Comorbidities; Length of admission; Living alone<br>Other: Education; Presence of a caregiver | Functional ability (BADLs) (continuous variable) | OR 1.4 (1.1-1.9) |
| | | Length of admission (Days) | OR 1.1 (1.0-1.1) |
| Smith 2009 | Sex; Living alone; Functional ability; Mobility; Prior Care<br>Other: Behaviour; Sleep; Weight Change; Readiness to Learn; Pain; Readmission; Risk of mortality; Race; Falls risk; Understanding of illness; Abnormal affect; Impaired level of consciousness; Presence of caregiver | Sex (male *vs* female) | OR 1.5 (1.26-1.77) |
| | | Living alone | OR 1.75 (1.43-2.14) |
| | | Functional ability (help with dressing) | OR 1.63 (1.34-1.98) |
| | | Falls risk | OR 2.25 (1.78-2.84) |
| | | Understanding of illness | OR 2.07 (1.58-2.71) |
| | | Abnormal affect | OR 1.80 (1.36-2.38) |
| | | Impaired level of consciousness | OR 1.76 (1.31-2.32) |
| | | Presence of caregiver | OR 0.76 (0.65-0.97) |
| | | Other: Education | OR 0.74 (0.58-0.94) |

*Table 3.6 continued overleaf*

***Table 3.6 continued***

| Study ID | Potential predictors evaluated | Statistically significant predictors | | |
|---|---|---|---|---|
| | | Predictor | | Odds Ratio (OR) or Risk Ratio (RR) (95% Confidence Interval) |
| Wong 2010* | Age; Sex; Dementia; Admission diagnosis; Length of admission<br>Other: Presence of spouse; Presence of child | Age (years) | | RRR 1.34 |
| | | Dementia | | RRR 7.50 |
| | | Admission diagnosis | Gastrointestinal cancer | RRR 1.25 |
| | | | Lung cancer | RRR 2.22 |
| | | | Bladder cancer | RRR 0.51 |
| | | | Schizophrenia | RRR 3.89 |
| | | | Epilepsy | RRR 1.33 |
| | | | Heart Failure | RRR 0.65 |
| | | | Cerebrovascular disease | RRR 11.55 |
| | | | Chronic obstructive pulmonary disease | RRR 0.73 |
| | | | Alcoholic liver disease | RRR 4.03 |
| | | | Coxarthrosis | RRR 4.93 |
| | | | Gonarthrosis | RRR 3.89 |
| | | | Glomerular disorders | RRR 0.32 |
| | | | Intracranial injury | RRR 2.21 |
| | | | Fracture of elbow & forearm | RRR 2.41 |
| | | | Fracture of femur | RRR 9.30 |
| | | | Fracture of ankle/lower leg | RRR 8.18 |
| | | Length of admission (days) | | RRR 1.12 |
| | | Presence of spouse | | RRR 0.48 |
| | | Presence of child | | RRR 1.17 |

**Data reported on significant predictors for nursing home admission,* versus *home with home care and home for the elderly care. Reported in text as relative risk ratios with standard error and annotation to denote statistical significance*

*Table 3.6 continued overleaf*

***Table 3.6 continued***

| Study ID | Potential predictors evaluated | Statistically significant predictors | |
|---|---|---|---|
| | | **Predictor** | **Odds Ratio (OR) or Risk Ratio (RR) (95% Confidence Interval)** |
| Zureik 1995 | Age; Living alone; Patient wishes; Family wishes; Cognitive impairment; Functional ability; Comorbidities; Admission diagnosis; Prior care | Age (>85 *vs* ≤85) | OR 1.8 (1.1-2.9) |
| | | Living alone | OR 1.9 (1.2-3.3) |
| | | Family wishes: No opinion/carer<br>Opposition to going home | OR 2.9 (1.9-4.3)<br>OR 8.2 (3.5-18.9) |
| | | Mild 'mental alteration'<br>Moderate 'mental alteration'<br>Severe 'mental alteration' | OR 1.4 (1.0 -1.7)<br>OR 1.8 (1.1-2.8)<br>OR 2.3 (1.3-4.8) |
| | | Functional ability (ADL score on admission)<br>1-3<br>4-6 | <br>OR 1.5 (1.0-2.0)<br>OR 2.1 (1.5-3.9) |
| | | Comorbidities (chronic conditions; degree of fatality)<br>Non-fatal<br>Fatal | <br><br>OR 2.1 (1.3-3.3)<br>OR 4.3 (1.7-10.7) |

***Footnotes:*** *ADL – activities of daily living; BADLs – basic activities of daily living; CAM – confusion assessment method; C-MMSE – Chinese Mini Mental State Examination D – development cohort; IADLs – instrumental activities of daily living; V – validation cohort*

Three studies examined the effects of a single factor on the outcome of care home admission, adjusted for other potential confounders. One determined that Malnutrition, as determined by the Prognostic Inflammatory and Nutritional Index ≥ 25 was associated with care home admission RR 2.04 (1.23-3.38) (Bonnefoy *et al*., 1998). Being unmarried was also associated with an increased risk, OR 2.67 (2.22-3.06) (Gordon and Rosenthal, 1995). The Risk Index for Geriatric Acute Medical Admissions (RIGMA), adjusted for age, was associated with care home admission for those with 3 to 5 deficits OR 1.34 (1.05-1.72) (Romero-Ortuno *et al*., 2014).

One study evaluated a series of routinely-collected biochemical test results on the likelihood of care home admission, adjusted for likely confounding factors (Brown *et al*., 2012). None of the observed associations between abnormal test results and care home admission persisted after adjustment (Brown *et al*., 2012).

One study presented binary logistic regression analysis with Wald statistics of age (years) 8.39 (p=0.004) and delirium (positive Confusion Assessment Method) 7.04 (p=0.008) associated with care home admission (Adamis *et al*., 2006). Non-statistically significant predictors were sex, cognitive impairment, comorbidities and functional ability (Adamis *et al*., 2006).

One study examined the correlation between predictors and discharge to nursing home care and concluded that dependency (Spearman's rank-order correlation rs -0.274) and active medical problem count (rs -0.336) were negatively correlated with this outcome (Astell *et al*., 2008). The study compared discharge to home, to nursing home or death and found that those with highest dependency and greater number of medical problems were most likely to die as inpatients. Those who had lowest dependency and fewer medical problems, however, were discharged home (Astell *et al*., 2008). The other variables evaluated but not found to be statistically significant were: dementia severity, behavioural problems, social problems, treatment for psychosis and treatment for depression (Astell *et al*., 2008).

Two studies presented unadjusted analyses which only examined a single predictor (Corsinovi *et al*., 2009, Van Nes *et al*., 2001). Malnutrition, as evaluated using the Mini-Nutritional Assessment was associated with higher risk of discharge to a nursing home (malnourished 20.3% *vs* not 7.7%, p<0.001) (Van Nes *et al*., 2001). Experiencing a fall at any point during admission was associated with nursing home placement (any fall 12.9% *vs* no fall 5.6%; p<0.005) (Corsinovi *et al*., 2009).

#### 3.3.5.2 Quantitative synthesis

Meta-analysis was performed on five predictors of care home admission from acute general hospital settings: age, female sex, delirium, dementia & cognitive impairment and functional dependency (**Table 3.7 & Figures 3.4-3.8**). Data for the quantitative synthesis came from 11 of the included studies, with factors selected where there were data available in three or more studies. Predictor data were included whenever the predictor was measured, irrespective of statistical significance in the individual studies.

**Table 3.7: Results of quantitative synthesis**

| Predictors | Number of studies | Number of participants | Pooled OR (95% CI) | $I^2$ % (Statistical heterogeneity) | GRADE assessment | Rationale |
|---|---|---|---|---|---|---|
| Age (per year) | 5 studies<br>6 datasets* | 4,431 | **1.02 (1.00-1.04)** | 0 | ⊕⊕⊕⊖<br>**Moderate quality evidence** | Downgraded due to risks of selection bias and reporting bias |
| Female sex | 5 studies | 8,312 | **1.41 (1.03-1.92)** | 15 | ⊕⊕⊖⊖<br>**Low quality evidence** | Downgraded due to risks of selection bias and reporting bias and inconsistency |
| Dementia & cognitive impairment | 5 studies<br>6 datasets* | 4,018 | **2.14 (1.24-3.70)** | 2 | ⊕⊕⊖⊖<br>**Low quality evidence** | Downgraded due to risks of selection bias and reporting bias and inconsistency |
| Delirium | 3 studies<br>4 datasets* | 3,267 | **1.61 (0.82-3.17)** | 20 | ⊕⊖⊖⊖<br>**Very low quality evidence** | Downgraded due to risks of selection bias, inconsistency and imprecision |
| Functional dependency | 6 studies | 7,796 | **2.06 (1.58-2.69)** | 0 | ⊕⊕⊕⊖<br>**Moderate quality evidence** | Downgraded due to risks of selection bias and reporting bias |

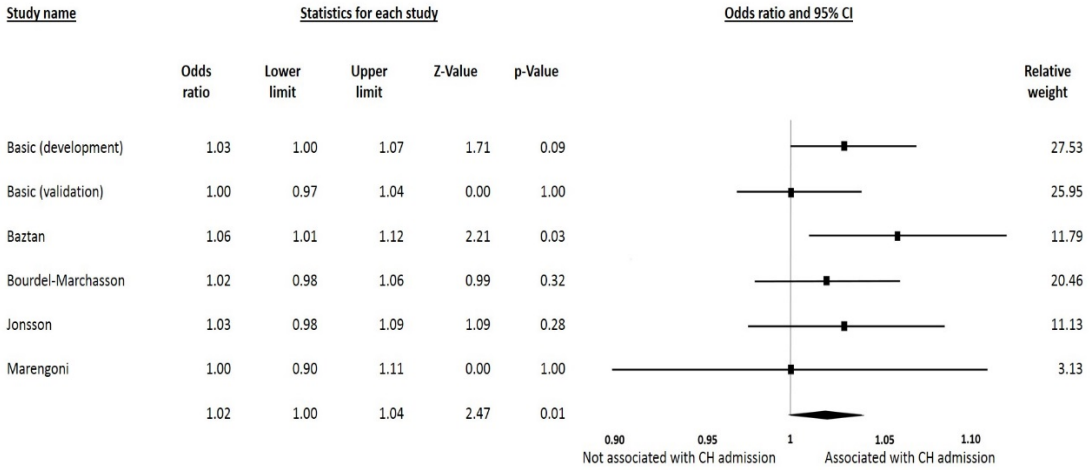
***Notes**: * data from development and validation cohorts within the same study;*

*CI – confidence interval; GRADE – Grading of Recommendations Assessment, Development and Evaluation*

Care home admission was associated with functional dependency (Pooled OR 2.06 95%CI 1.58-2.69; 7,796 participants; six studies; moderate quality evidence); dementia and cognitive impairment (Pooled OR 2.14 95%CI 1.24-3.70; 4,018 participants; five studies; low quality evidence); female sex (Pooled OR 1.41 95%CI 1.03-1.92; 8,312 participants; five studies; low quality evidence) and; increased age (per year increase) (Pooled OR 1.02 95%CI 1.00-1.04; 4,431 participants; five studies; moderate quality evidence).

There was no evidence that delirium was associated with care home admission (Pooled OR 1.61 95%CI 0.82-3.17; 3,267 participants; three studies; very low-quality evidence).

**Figure 3.4: Forest plot for association of age with care home admission**




*Footnote: Note scale for Age forest plot ranges from 0.90-1.10. Unable to adjust scale in Comprehensive Meta-Analysis software, thus above figure created in Microsoft PowerPoint based on CMA results*

**Figure 3.5: Forest plot for association of female sex with care home admission**

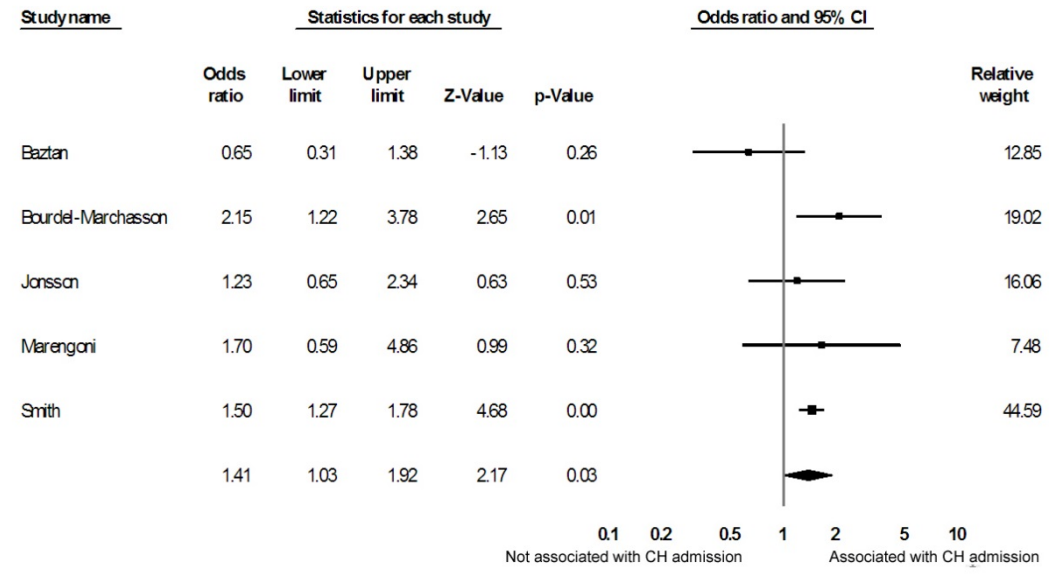


**Figure 3.6: Forest plot for association of dementia & cognitive impairment with care home admission**

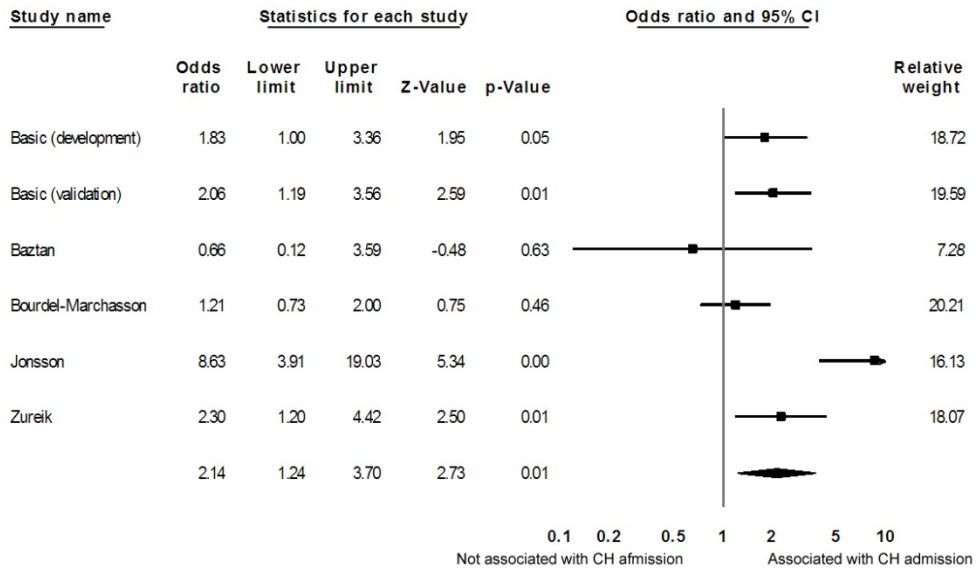



**Figure 3.7: Forest plot for association of delirium with care home admission**

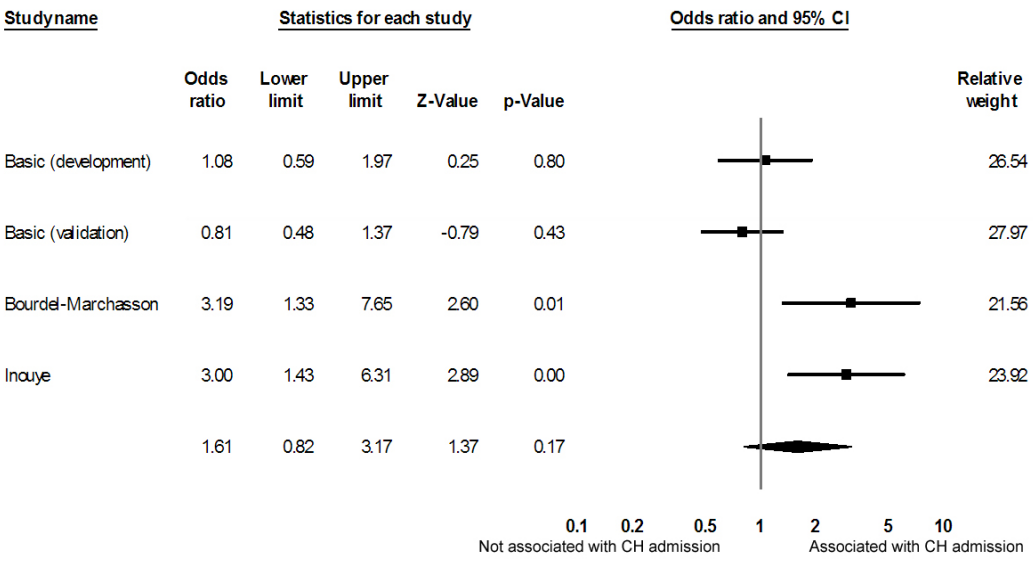
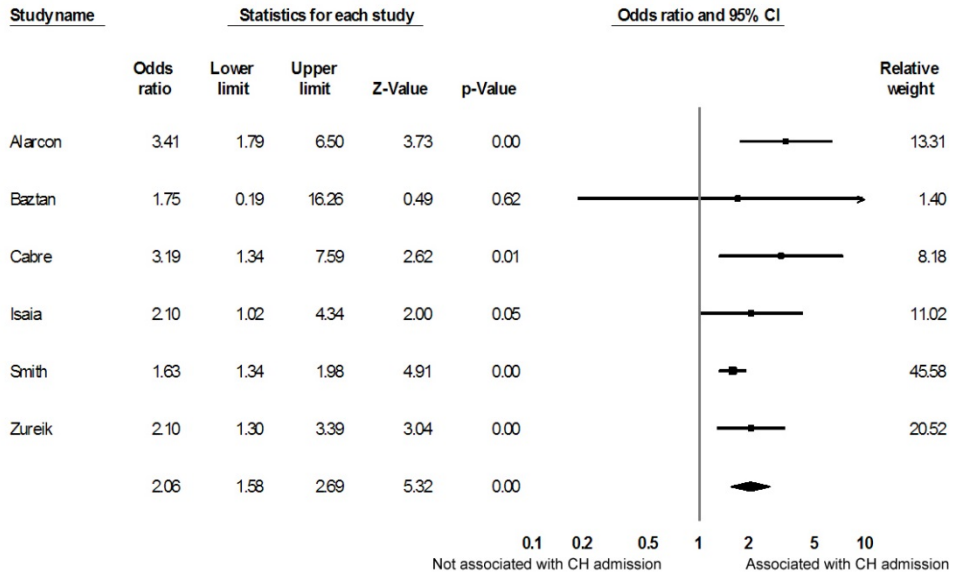


**Figure 3.8: Forest plot for association of functional impairment with care home admission**




#### 3.3.5.3 Stroke studies

Ten of the 16 studies presented multivariate models with ORs or RRs of predictors, summarised in **Table 3.8**. Advanced age, more severe stroke (determined by the National Institute for Health Stroke Scale [NIHSS] or modified Rankin Scale) and evidence of cardiovascular disease were associated with increased likelihood of care home admission, although it was not possible to pool these data to produce summary estimates. Two of these studies only reported data where statistically significant associations were identified (Pinedo *et al*., 2014, Brosseau *et al*., 1996).

There was no evidence of gender as a predictor of the need for care home admission from three studies (Béjot *et al*., 2012, Rundek *et al*., 1998, Treger *et al*., 2008). Increased length of stay was associated with this outcome in only one of the three studies which evaluated it (Treger *et al*., 2008, Rundek *et al*., 1998, Béjot *et al*., 2012). Being unmarried, divorced or widowed, or having 'poor social support' were associated with an increased likelihood of admission to care home in two studies (Pinedo *et al*., 2014, Brosseau *et al*., 1996), with no evidence of an association between this outcome and living alone prior to stroke in two others (Rundek *et al*., 1998, Schlegel *et al*., 2003). Having a history of stroke was evaluated in only one study, which found evidence of an association with care home admission. Evidence of prior comorbidities and experiencing complications during the inpatient stay also demonstrated positive associations with care home admission at discharge.

The remaining six studies adopted different statistical approaches to determine predictors of care home admission. Portelli *et al.* present the univariate analysis of the included predictors, but do not report their multivariate model results, discussing instead the extent of variation explained by age, length of stay and function (using Barthel Index) as 54% and that 22% of variation was due to total Glasgow Coma Scale and the ability to walk unaided (Portelli *et al*., 2005).

Two studies present unadjusted analyses of a single predictor (McManus *et al*., 2009, Ramirez-Moreno *et al*., 2008). Delirium within 14 days of admission was associated with an increased risk of care home admission, OR 14 (3.05-64.37) (McManus *et al*., 2009). Treatment in a specialist Neurology ward rather than a General ward was associated with reduced risk of care home admission (p 0.006) (Ramirez-Moreno *et al*., 2008).

Koyama *et al.* performed logistic regression analysis to investigate variables associated with discharge destination, presenting their data as parameter estimates with their standard error and p-value (Koyama *et al*., 2011). They identified that age, FIM (Functional Independence Measure) score on admission and discharge, household members and presence of a spouse had statistically significant associations with admission to a care home (Koyama *et al*., 2011).

Murie-Fernández *et al.* identified a correlation of 0.308 ($p<0.01$) between delay in starting neurorehabilitation and the need for admission to a care home at discharge (Murie-Fernández *et al*., 2012).

Kammersgaard *et al.* investigated the role of early infection on prognosis and identified no statistically significant association between this and care home admission (Kammersgaard *et al*., 2001).

**Table 3.8: Multivariate predictors of care home admission from stroke studies**

| Study ID | Potential predictors evaluated | Statistically significant predictors | |
|---|---|---|---|
| | | Predictor | Odds Ratio OR/Risk Ratio RR (95% Confidence Interval) |
| Béjot 2012 | Age; Sex; Dementia; Functional ability; Comorbidities; Length of stay; Medication use before admission; Smoking; Stroke severity; Extent of stroke symptoms; Type of facility | Age ≥ 80 at admission<br>Age ≥ 80 at discharge | OR 28.52 (3.47-234.72)<br>OR 9.00 (1.07-75.68) |
| | | Dementia | OR 3.21 (1.42-7.24) |
| | | modified Rankin Scale (mRS) 2-3<br>modified Rankin Scale (mRS) 4-5 | OR 3.58 (1.46-8.78)<br>OR 74.44 (27.35-202.63) |
| | | Heart Failure | OR 2.65 (1.12-6.27) |
| | | Anticoagulant use before admission<br>Antiplatelet use before admission | OR 5.55 (1.97-15.66)<br>OR 2.28 (1.17-4.44) |
| | | Smoking | OR 0.41 (0.19-0.92) |
| | | Stroke severity (NIHSS >20) | OR 44.23 (15.79-123.91) |
| | | Upper limb weakness on admission | OR 3.38 (1.56-7.31) |
| | | Upper and lower limb weakness on admission | OR 2.96 (1.36-6.42) |
| | | Not specified limb weakness on admission | OR 3.39 (1.09-10.54) |
| Brosseau 1996 | Biologic, sociodemographic and psychosocial factors (full list not provided), only statistically significant variables described: Functional status on admission; social support; ability to walk; medical complications | Functional Independence Measure (FIM) | OR 0.96 (0.94-0.99) |
| | | Social support | OR 2.60 (1.60-4.20) |
| | | Ability to walk (yes) | OR 0.15 (0.031-0.74) |
| | | Medical complications (yes) | OR 4.40 (1.10-19.0) |
| Ifejika 2015 | Age, Sex, Ethnicity, NIHSS, t-PA therapy, UTI on stroke service, UTI on neurorehabilitation service, Length of stay, Admission FIM, Discharge FIM, FIM efficiency | Age (in years) | OR 1.04 (1.01-1.08) |
| Kwan 2007 | Post-stroke infection<br>Adjusted for: age, mRS, GCS on admission, OCSP | Post-stroke infection | OR 1.86 (1.00-3.43) |
| Lai 1998 | Age; Sex; Admission diagnosis; Length of admission; Comorbidities; Marital status; Swallowing difficulty; Stroke deficits | Age (in years) | RR 1.2 (1.10-1.20) |
| | | Length of admission (Days) | RR 1.1 (1.10-1.20) |
| | | Deficit in Language | RR 3.1 (1.4-6.5) |
| | | Deficit in Facial | RR 2.5 (1.30-4.80) |
| | | Deficit in Leg | RR 2.6 (1.20-6.00) |

*Table 3.8 continued overleaf*

***Table 3.8 continued***

| Study ID | Potential predictors evaluated | Statistically significant predictors | |
|---|---|---|---|
| | | **Predictor** | **Odds Ratio OR/Risk Ratio RR (95% Confidence Interval)** |
| Pinedo 2014 | Comorbidities, Functional status (Barthel Index); Civil status, Social risk (Gijon scale), Dysphagia, Trunk control test score | Unmarried, divorced or widowed (*versus* married) | OR 9.17 (3.79-22.22) |
| | | High Charlson Index (*versus* none/low level) | OR 2.71 (1.27-5.77) |
| | | Total dependence on Barthel Index (*versus* other) | OR 2.95 (1.38-6.28) |
| Rundek 1998 | Age; Sex; Living alone; Admission diagnosis; Comorbidities; Race; Education | Age (≥65) | RR 2.3 (1.1-5.0) |
| | | Admission diagnosis (Non-lacunar stroke) | RR 2.0 (1.1-3.6) |
| Schlegel 2003 | Age; Living alone; Functional status; Admission diagnosis; Stroke severity (NIHSS) | NIHSS >13 (*vs* ≤5) | OR 310 (7.8-12434) |
| Treger 2008 | Age; Sex; Dementia; Admission diagnosis; Comorbidities; Stroke severity (NIHSS) | Age (per 10 year unit) | RR 1.93 (1.5-2.5) |
| | | Dementia | RR 4.41 (2.49-7.82) |
| | | Admission diagnosis: Stroke type (Intracranial haemorrhage *vs* other) | RR 3.51 (1.73-7.13) |
| | | Comorbidities: Prior stroke | RR 1.69 (1.05-2.71) |
| | | NIHSS 6-10 (*vs* ≤5)<br>NIHSS 11-16 (*vs* ≤5)<br>NIHSS >16 (*vs* ≤5) | RR 2.28 (1.18-4.42)<br>RR 11.45 (6.13 - 21.40)<br>RR 38.20 (16.65-87.60) |
| Turco 2013 | Age, Sex, Living alone, type of stroke, time from stroke to rehab admission, albumin level, >4 medications on admission, IADLs lost, Delirium, Malnutrition, Urinary catheter (on admission to rehab), CRP levels, Functional status (Barthel index), Tinetti score, Cognitive function (MMSE), Mood (GDS), Adverse clinical events, length of stay | Delirium on admission | OR 7.23 (4.79-10.91) |
| | | Malnutrition | OR 5.71 (1.62-20.09) |
| | | Catheter on admission | OR 4.56 (1.36-15.28) |
| | | Barthel Index score on admission | OR 0.94 (0.91-0.97) |

***Notes:*** *FIM – Functional Independence Measure; GCS – Glasgow Coma Scale; GDS – Geriatric Depression Scale; IADLs – Instrumental Activities of Daily Living; MMSE – Mini Mental State Examination; mRS – modified Rankin Scale; NIHSS – National Institute for Health Stroke Scale; OCSP – Oxford Community Stroke Project; t-PA – tissue plasminogen activator; UTI – urinary tract infection*

#### 3.3.5.4 Acute specialist population studies

Seven studies were set in specialist areas, based on the diagnosis of the included individuals. Of these, four presented multivariate models, summarised in **Table 3.9**. Age was the only predictor found to be statistically significant in all four studies. Predictors evaluated were often highly specific to the specialist population and therefore likely to lack generalisability.

Two studies present analysis of a single factor adjusted for potential confounding variables (Sood *et al*., 2011, Uthamalingam *et al*., 2011). In dialysis patients, functional impairment, using an Activities of Daily Living (ADL) score within 24 hours of admission combined with age, was associated with an increased risk of discharge to an assisted care facility OR 1.25 (1.15-1.37) (Sood *et al*., 2011). In older adults presenting with acute decompensated heart failure, the presence of delirium on admission, defined using the Confusion Assessment Method (CAM), was associated with an increased risk of nursing home admission OR 2.66 (1.78-3.97), adjusted for dementia and ADL (Uthamalingam *et al*., 2011).

One study presented an unadjusted evaluation of the risk of a hospital-sustained femoral fracture being associated with an increased risk of care home admission compared with those sustaining the injury in the community RR 2.80 (1.10-7.09) (Murray *et al*., 2007).

**Table 3.9: Multivariate predictors of care home admission from specialist population studies**

| **Study ID** *Specialist population* | **Potential predictors evaluated** | **Statistically significant predictors** | |
|---|---|---|---|
| | | **Predictor** | **Odds Ratio (OR) Relative Rate Ratio (RRR) (95% Confidence Interval)** |
| Aitken 2010 *Trauma* | Age; Sex; Length of admission; Admission diagnosis<br>Other: Region with most severe injury; Level of hospital care; ICU admission; Injury severity score; Transfer from another hospital | Age (≥85 *vs* 65-74) | RRR 10.41 (6.61-16.37) |
| | | Length of admission (≥15 days *vs* 1-3 days) | RRR 5.30 (2.62-10.72) |
| | | Admission diagnosis (internal organ *vs* fracture) | RRR 0.16 (0.04-0.71) |
| | | Other: Level of hospital care (Regional *vs* tertiary) | RRR 1.81 (1.27-2.56) |
| | | Other: Injury severity score (≥15 *vs* 0-9) | RRR 2.01 (0.81-5.01) |
| Bogan 2014 *Carbapenem-resistant* Enterobacteriaceae *(CRE)* | Age; Functional ability; Admission diagnosis; Comorbidities<br>Other: ICU stay; Permanent foreign device | Functional ability: Dependent (Katz criteria) | OR 3.2 (1.3-7.7) |
| | | Admission diagnosis (specifically CRE isolation) | OR 13.7 (4.3-44.4) |
| | | Other: ICU stay (in past 3 months) | OR 4.9 (2.1-11.2) |

*Table 3.9 continued overleaf*

***Table 3.9 continued***

| **Study ID**<br>*Specialist population* | **Potential predictors evaluated** | **Statistically significant predictors** | |
|---|---|---|---|
| | | **Predictor** | **Odds Ratio (OR) Relative Rate Ratio (RRR) (95% Confidence Interval)** |
| Neuhaus 2014<br>*Isolated acute proximal humerus fractures* | Age; Sex; Dementia; Comorbidities; Length of admission<br>Other: Treatment; Transfusion; Post-haemorrhagic anaemia | Age (years) | OR 1.07 (1.07-1.08) |
| | | Sex (Male) | OR 1.3 (1.2-1.3) |
| | | Dementia | OR 0.76 (0.72-0.81) |
| | | Acute renal failure<br>Congestive heart failure<br>Diabetes<br>Chronic pulmonary disease<br>Pneumonia<br>Hypertensive disease<br>Obesity | OR 2.3 (2.1-2.6)<br>OR 2.2 (2.1-2.3)<br>OR 2.0 (1.9-2.1)<br>OR 1.5 (1.4-1.5)<br>OR 1.3 (1.1-1.4)<br>OR 0.72 (0.70-074)<br>OR 0.32 (0.28-0.36) |
| | | Length of admission (days) | OR 1.13 (1.13-1.14) |
| | | Internal fixation *vs* non-operative<br>Arthroplasty *vs* non-operative | OR 0.54 (0.52-0.56)<br>OR 0.33 (0.32-0.35) |
| | | Transfusion | OR 1.6 (1.5-1.7) |
| | | Post-haemorrhagic anaemia | OR 0.65 (0.61-0.69) |
| Sacks 2011<br>*Trauma* | Age; Sex; Admission diagnosis<br>Other: Injury severity score; insurance; race | Age (>60) | OR 13.58 (12.89-14.32) |
| | | Sex (Male) | OR 0.57 (0.56-0.58) |
| | | Admission diagnosis: (Penetrating *vs* blunt trauma) | OR 0.37 (0.35-0.40) |
| | | Injury severity score (>15 *vs* <8) | OR 1.70 (1.66-1.74) |
| | | Uninsured (*vs* insured)<br>Medicare (*vs* insured) | OR 0.76 (0.73-0.80)<br>OR 3.24 (3.15-3.33) |
| | | Black race (*vs* White)<br>Hispanic race (*vs* White) | OR 0.77 (0.74-0.79)<br>OR 0.55 (0.53-0.58) |

***Notes:*** *CRE – Carbapenem-Resistant* Enterobacteriaceae*; ICU – intensive care unit*

#### 3.3.5.5 Rehabilitation setting studies

Only two (Pautex *et al*., 2005, Torpilliesi *et al*., 2010) of the seven rehabilitation setting studies presented the results of their multivariate analyses, summarised in **Table 3.10.** These found that poorer cognitive function (OR 10.66) and delirium superimposed on dementia (OR 2.0) are both associated with an increased likelihood of discharge to a care home after rehabilitation. In a study of 75 participants, Haley *et al.* did not find any statistically significant predictors of care home admission: not even frailty measured using the Edmonton Frail Scale (Haley *et al*., 2014).

The other four studies adopted different methods of analysis. Jupp *et al.* describe the development of a GEMS (gait, eyesight, mental state, sedation) tool to identify those who will require care home placement after hospitalisation (Jupp *et al*., 2011). Data are reported as p-values with confidence intervals, identifying abnormal vision, impaired cognitive function, gait abnormalities and use of tranquillisers as statistically significant predictors (Jupp *et al*., 2011). It is noteworthy that their study uses the composite of death or discharge home as the reference category (Jupp *et al*., 2011).

Lindenberg *et al.* created a logistic regression model for discharge destination, their model including total BOOMER (Balance Outcome Measure for Elder Rehabilitation) score <4, inability to perform a ten-metre walk test and rehabilitation length of stay (Lindenberg *et al*., 2014). This model accounted for 60.7% p=0.002 of variability in the outcome destination in this study sample (Lindenberg *et al*., 2014).

Tamler *et al.* report their data as differences in proportions, finding that older patients (mean 72.2 *vs* 59.9 p <0.005) and those with lower social support (BLISS Beaumont Lifestyle Inventory of Social Support mean score 4.0 *vs* 9.3, p <0.0006) were more likely to be discharged to nursing homes than to home (Tamler and Perrin, 1992)

**Table 3.10: Multivariate predictors of care home admission from rehabilitation population studies**

| Study ID | Potential predictors evaluated | Statistically significant predictors | |
|---|---|---|---|
| | | **Predictor** | **Odds Ratio (OR) Relative Rate Ratio (RRR) (95% Confidence Interval)** |
| Pautex 2005 | Age, Sex, Living alone, regular caregiver, BADL (>1), MMSE (<24), GDS (≥1); Charlson index | MMSE (<24/30) | OR 10.66 (2.23-50.87) |
| Torpilliesi 2010 | Age, gender, BMI, comorbidity, functional status on admission, cognitive 'classification' | Age | OR 1.1 (1.0-1.1) |
| | | Barthel index on admission | OR 0.97 (0.97-0.98) |
| | | Delirium superimposed on dementia | OR 2.0 (1.2-3.4) |

***Notes:*** *BADL – Basic Activities of Daily Living; BMI – Body Mass Index; GDS – Geriatric Depression Score; MMSE – Mini-Mental State Examination*

Panella *et al.* modified an existing rehabilitation screening score and found that having a Rasch-modified BRASS score (Blaylock Risk Assessment Screening Score) of 12 was associated with an increased risk of care home admission (RR 2.1 95%CI 1.7-2.5) (Panella *et al*., 2012). The score incorporates measures of behaviour, hospitalisation, mobility, cognition and functional status (Panella *et al*., 2012).

### *3.3.6 Sub-group analyses*

***Residential* vs *nursing care***: Only one study evaluated predictors for two levels of institutional care, defined as nursing homes or homes for the elderly (Wong *et al*., 2010). Two factors were associated with 'home for the elderly' care but not nursing home care: female sex and female spouse (Wong *et al*., 2010). Five diagnoses were associated with nursing home care but not 'home for the elderly' care: Alzheimer's disease, heart failure, chronic obstructive pulmonary disorder, bladder cancer and glomerular disorders (Wong *et al*., 2010). All other variables which were associated with nursing home care (**Table 3.6**) were also associated with 'home for the elderly' care (Wong *et al*., 2010).

***Country of origin***: No specific trends were noted by country of origin. In view of the heterogeneity of the data and difficulties in pooling results this has not been evaluated formally.

***Age <65* vs *≥65****:* The four studies where mean age was <65 include four clinically-distinct populations: bacteraemia (Bogan *et al*., 2014), general medicine (Gordon and Rosenthal, 1995), trauma (Sacks *et al*., 2011) and stroke (Schlegel *et al*., 2003). Being aged >60 was associated with increased likelihood of care home admission in only one of these studies (Sacks *et al*., 2011).

***Timing of assessment of predictor****:* Three studies evaluated predictors of care home admission at time of hospital admission and at discharge (Béjot *et al*., 2012, Luk *et al*., 2009, Portelli *et al*., 2005). In one study individuals aged ≥80 continued to have a statistically significant positive association with care home admission at both admission (OR 28.52 95%CI 3.47-234.72) and discharge (OR 9 95%CI 1.07-75.38) (Béjot *et al*., 2012). Luk *et al.* report results of functional assessment, mobility, cognition, albumin, incontinence, catheterisation and pressure sores at admission and discharge with statistically significant proportional differences at each stage between those who are discharged home and those admitted to a care home (Luk *et al*., 2009). Their multivariate results only include statistically significant predictors (**Table 3.8**) (Luk *et al*., 2009).

Portelli *et al.* only report their univariate analysis. Age, female sex, previous stroke, being retired, living alone, low Barthel Index, total anterior circulation infarction, low Glasgow Coma Score, reduced function in arms and legs, being unable to walk and experiencing communication difficulties were all associated with elevated risk of care home admission (Portelli *et al*., 2005). At discharge: care in an acute geriatric or general rehabilitation ward, catheterisation, low Barthel Index and prolonged length of stay, were associated with care home admission (Portelli *et al*., 2005).

***Dementia and delirium**:* Six studies evaluated the role of diagnosed dementia as a predictor of care home admission (Basic and Shanley, 2015, Cabré and Serra-Prat, 2004, Wong *et al*., 2010, Béjot *et al*., 2012, Treger *et al*., 2008, Neuhaus *et al*., 2014). In four of these there was evidence of a statistically significant positive association between dementia and care home admission (Basic and Shanley, 2015, Wong *et al*., 2010, Béjot *et al*., 2012, Treger *et al*., 2008). In one study dementia was associated with a lower risk of care home admission in those with a proximal humerus fracture, although no account was made for disease severity or delirium (Neuhaus *et al*., 2014).

Eight studies evaluated delirium as a predictor of care home admission (Adamis *et al*., 2006, Basic and Shanley, 2015, Bourdel-Marchasson *et al*., 2004, Cabré and Serra-Prat, 2004, Inouye *et al*., 1998, McManus *et al*., 2009, Turco *et al*., 2013, Uthamalingam *et al*., 2011). There was evidence of a statistically significant positive association between delirium and care home admission in six studies. Although the included populations and methods of analysis were heterogeneous, they all took account of cognitive function (Adamis *et al*., 2006, Bourdel-Marchasson *et al*., 2004, Inouye *et al*., 1998, McManus *et al*., 2009, Turco *et al*., 2013, Uthamalingam *et al*., 2011).

Torpilliesi *et al.* found that delirium superimposed on dementia was associated with an increased risk of care home admission OR 2.0 (1.2-3.4) among consecutive older patients in a rehabilitation and aged care unit on multivariate analysis (Torpilliesi *et al*., 2010). No other studies specifically evaluated delirium superimposed on dementia.

## 3.4 DISCUSSION

### *3.4.1 Summary of evidence*

This review included a study population of 1,457,881 participants from 16 countries and 53 relevant studies. In spite of the size of the available evidence base, studies are heterogeneous and reporting quality is low, with risk of bias. Many potentially relevant predictors are not reported. The presentation of the results is largely narrative, with only 11 studies contributing to quantitative synthesis.

The quantitative synthesis showed that functional dependency and dementia increase the risk of care home admission two-fold, with female sex increasing risk by 1.4, but evidence here was of moderate – low quality. Age, per year increase, was associated with a small increased risk with OR of 1.02 from moderate quality evidence. While these predictors have clinical validity, they are not particularly discriminatory in predicting those who will need care home admission in practice, where older females with cognitive and functional impairments are prevalent among hospitalised adults.

There was no evidence, from the data which could be pooled, that delirium was associated with an increased risk of care home admission, although the evidence was assessed to be of very low quality, due to risk of bias, inconsistency of results and imprecision. Only three studies, with a total of four datasets, contributed data to this result and the summary estimate confidence interval is broad (OR 1.61; 95%CI 0.82-3.17). This reflects that two of the studies identified delirium as a predictor associated with care home admission, while the other study did not. The

prevalence of delirium was ~40% in this study and this may have contributed to the lack of predictive power in these datasets.

Variables identified in other acute general setting studies indicated that falls and length of stay may also be associated with an increased risk, although these data could not be pooled.

The studies in stroke populations found that age, increased severity of stroke and history of cardiovascular disease, were associated with increased risk of care home admission, but, again, heterogeneity in presentation of the data prevented quantitative synthesis.

The 'acute specialist' and 'rehabilitation setting' studies provide little generalisable data on predictors of care home admission, with increased age showing a consistent positive association, but other variables were specific to the individual studies.

From the pre-specified subgroup analyses: *level of care* was described in only one study; there were no clear trends observed based on *country of origin*; in the four studies which included populations with a *mean age <65 years*, age seemed less important as a predictor within this sample. The *timing of assessment of predictors* was limited by available data, with only admission and discharge used as sampling points. Admission has an intuitive advantage over discharge when considering predictors of hospitalisation outcome and data from time of discharge are likely to be affected by survivor bias.

Social support, family and patient wishes, the availability and costs of social care and clinical variables such as continence, frailty and falls were seldom evaluated. No studies considered in-hospital care processes or adverse events and their impact on outcome.

### *3.4.2 Comparison with existing literature*

The predictors of care home admission from hospital are similar to those from the community in several respects. Increased age has been identified as a predictor of care home admission in community cohorts (Luppa *et al*., 2010) and specifically among those with dementia (Eska *et al*., 2013). Female sex as a predictor variable has produced inconsistent results in community cohorts (Luppa *et al*., 2010), although there was evidence of an association found in general hospitalised populations.

Dementia and cognitive impairment have also been identified as predictors of care home admission (Zekry *et al*., 2009, Hajek *et al*., 2015), with the severity of dementia (Gaugler *et al*., 2009, Toot *et al*., 2017) and Behavioural and Psychological Symptoms of Dementia (BPSD) as important predictors (Toot *et al*., 2017). While dementia and cognitive impairment were identified as predictors, this review was limited by the varied measures used to evaluate these states across the included studies. Although cognitive test scores were considered, no formal measure of disease severity was used. Such heterogeneity in measurement has been observed before (Lees *et al*., 2012, Harrison *et al*., 2016) and is a limitation for research in this field. None considered BPSD as a potential predictor among inpatients, perhaps reflecting inclusion of those in the general hospital, rather than specialised psychiatry settings.

The review data regarding delirium are difficult to pool, due to the varied methods applied in the included studies. Although six of the eight studies identified a positive association, most

studies did not evaluate this as a predictor. The quantitative synthesis identified a lack of evidence about delirium, rather than a lack of effect of delirium as a predictor of care home admission. The role of delirium has been comparatively under-researched among hospital inpatients. Previous systematic review data included follow-up after hospital discharge over an average of 14 months, these showed that delirium was associated with increased risk of care home admission (Witlox *et al*., 2010). Further research is required on inpatient cohorts to better understand the nature of the observed relationship to try to determine its mechanisms.

Dependency in ADL has also been established as a predictor of care home admission among inpatients (De Buyser *et al*., 2014) and in those with dementia in community settings (Luppa *et al*., 2008, Gaugler *et al*., 2009). Again there was a lack of standardisation in how this was measured or determined among the included studies in the present review. While the use of scales may represent the needs of disease-specific populations, such as the National Institutes of Health Stroke Scale (NIHSS) being used in stroke, among the general settings measures included established scales, such as the Barthel Index, and descriptions of difficulties with ADL or specific domains of function.

Living alone, widowhood and caregiver burden are factors which have been considered in greater detail in non-hospital cohorts (Verbeek *et al*., 2015, Eska *et al*., 2013, McCann *et al*., 2011). These are potentially important explanatory variables which may not be captured in healthcare data. Of note, caregiver stress has been shown to moderate the predictive effects of dementia severity on care home admission when this is measured (Gaugler *et al*., 2009). Furthermore, there is some evidence to suggest that caregiver burden can be modified with associated reduction in the need for institutional care (Mittelman *et al*., 2006). Luppa *et al.* developed a conceptual framework to consider factors affecting institutionalisation in people with dementia (Luppa *et al*., 2008). This separated factors into predisposing variables (including sociodemographic and relationship factors); needs variables (divided into primary and secondary stressors) and enabling variables (divided into personal resources, social resources and community-based care). All of these, including the desire to institutionalise, helped to suggest how the process may occur (Luppa *et al*., 2008). This framework assists in capturing the complex interplay between health-related factors, social factors and individual differences with respect to coping strategies, satisfaction and quality of life, which cannot be fully explored in the current healthcare-focused data on hospitalised cohorts.

### *3.4.3 Quality of evidence and limitations in available data*

In the risk of bias assessment selection bias was the most common issue identified. This reflects the pragmatic approach taken by studies looking at hospitalisation outcomes compared with the specific question of interest in this review. To illustrate, included studies often focused on assessing individual patients with a range of measurements and so placed exclusions based on diagnoses, transfers, escalation of care and availability of documentation. The current research question however sought to be inclusive of all those admitted to hospital who may be at risk of admission to a care home setting: exclusions for practical reasons thus result in a non-consecutive sample. Risk of bias assessment in this context allows an evaluation of how the conduct of the individual study affects the applicability of the findings of this review.

Methodological quality is an area requiring improvement for general population and dementia-specific studies of predictors of nursing home placement (Luppa *et al*., 2010, Luppa *et al*., 2008).

A second common issue found in the risk of bias assessment was that only one study had a protocol already in the public domain – allowing readers to evaluate the risk of reporting bias. The use of registration in clinical trials and publication of protocols has helped to ensure greater transparency in research and evaluation of successful and unsuccessful research (Dwan *et al*., 2011). Although these have been less common in observational research (Norris *et al*., 2013), improved use of protocols could lead to similar improvements in this field and is to be encouraged.

Although some of the studies were small, with a median sample size of 536 participants and much larger data sets contributing, evaluation of statistically significant predictors is limited not by sample size, but by methods of measurement. Failure to evaluate possible confounding variables was encountered in studies which presented unadjusted analyses, but also among those which did not evaluate the role of cognition, age, sex, comorbidity or function in these typically older cohorts. Furthermore, patient and family wishes were only evaluated in a single study, while other variables such as level of social care, financial support and caregiver stress were not considered. If these epidemiological studies are to lead to useful risk prediction and ultimately intervention studies, it is important that a wide range of predictors, particularly potentially reversible ones, are included.

Heterogeneity among the included studies was also significant. This occurred in the populations studied and the inclusion of highly specialised groups, such as those presenting with trauma or specific fractures. There was heterogeneity in study design – with some specifically investigating whether a factor of interest was predictive of care home admission, either with or without adjustment for other explanatory variables. The more common method was to investigate all possible predictors of care home admission using multivariate modelling, although the evaluation of confounding variables, such as cognition, was often not considered and methods of presenting data varied. In observational studies reporting predictors it is important that unadjusted analyses are reported to allow the reader to ascertain the importance of the different factors examined. There are various ways in which these can subsequently be analysed to explore the associations between the factors and the outcome. Adjusting for factors, such as age, may diminish the importance of this clinically important predictor of outcomes. Alternative approaches such as forced entry of age into models allows the relative importance of age to be observed, whereas stepwise models of analysis retain only factors which are independently associated with the outcome. The heterogeneity of approaches used by the included studies limited the scope to pool results.

Reporting of core information was considered sub-optimal in many of the included studies. This included transparent reporting, providing absolute values as well as proportions/percentages to help understand the completeness of the data and absolute numbers being discharged to a care home. Furthermore, the reporting only of variables which demonstrated statistically significant associations with the outcome of interest limits the usefulness of the data and can introduce bias as a result. Future research would benefit from use of the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement to ensure more complete reporting of methods and results (von Elm *et al*., 2008).

Only two studies described the nature of provision in the care home. This limits the ability of readers to determine if care home provision, and thus the study findings, are comparable with their own clinical or research practice. The need for a clear description of the components of care in this setting has been advocated by the international care home research community in view of international variation in terminology and practice (Sanford *et al*., 2015).

### *3.4.4 Strengths in review methodology & conduct*

This review was reported in accordance with the PRISMA statement (Moher *et al*., 2009). It is based on a comprehensive search strategy, inclusive of year and language of publication and the population of interest was clearly defined. A protocol was registered prospectively and the review was conducted as outlined. The role of independent reviewers in screening and reviewing full texts helped to ensure continuity of approach. Performing double data extraction on a quarter of the included studies also helped to ensure consistency. The risk of bias assessment is based on an established tool, RoBANS (Kim *et al*., 2013), modelled on the Cochrane Risk of Bias Assessment Tool (Higgins *et al*., 2011). This allowed for an in-depth evaluation of the included studies and the provision of summary diagrams to permit an overview of issues common in the included studies. Results have been presented based on the included populations, reflecting the clinical settings in which care is delivered in practice and avoiding grouping highly specialist populations with general unselected admissions. Quantitative synthesis has been carried out where data allowed and the quality of evidence has been evaluated using a recognised system, GRADE (Guyatt *et al*., 2008).

### 3.4.5 Limitations in review methodology & conduct

The systematic review may have excluded additional relevant studies which looked at predictors of care home admission if they evaluated change of residency at a fixed period of follow-up (e.g. six months). It will also have excluded studies using a composite outcome of care home admission and death. In seeking to identify observational studies, the review excluded qualitative studies reporting factors associated with care home admission from hospital and also intervention studies which may alter the likelihood of a hospitalised individual requiring care home admission.

A forward citation search was not performed on the included studies, which may increase the risk of bias from the search not capturing all of the available literature (Kuper *et al*., 2006). Studies were excluded if they reported only composite outcomes which included care home admission, or evaluated predictors of care home admission based on fixed time periods, e.g. three or six months. Exclusion of these studies may have reduced the available data on this topic.

In spite of using an existing tool, quality assessment is inherently subjective. The creation of the guidance (Appendix 3.3) to provide signalling to assessors and ensuring that an assessor evaluated all included studies were attempts to minimise variation in responses. No formal calculation was made of the extent of agreement between those performing double data extraction and any differences in response were resolved in discussion.

Although abstract authors were contacted to investigate if the research had subsequently been published, no attempt was made to contact authors where data were unclear or not reported in the published manuscript. This means that some of the figures – proportion discharged to a care home for example – are from available data and not the entire sample.

Separating the included populations into acute general settings, stroke studies, acute specialist populations and rehabilitation studies may have reduced the data available for quantitative synthesis. This was done however to ensure comparisons were fair and consistent with clinical practice. That only 11 studies are included in the meta-analysis introduces bias. From those studies which were combined, there is also heterogeneity in approach. The studies examined different combinations of predictors and thus the pooling of results is done with caution as each of the included studies will derive a different weight for the predictor based on the other factors considered. For three of the five comparisons, data originated from two cohorts within the same study and so are not independent. Measures of dementia, cognitive impairment and functional dependency varied between the pooled studies and data had to be excluded from studies which did not report multivariate models with odds ratios and confidence intervals. In addition, some studies considered single-point changes in cognition or difficulties with instrumental, rather than basic, ADL and so these could not be synthesised with those using different methods. These all limited the available data and raise concerns about how representative the included studies are in the quantitative synthesis.

GRADE is a recognised methodology, typically used when describing the body of available evidence on a topic in relation to a specific treatment or intervention. A decision was required as to whether to downgrade evidence from observational study designs, in keeping with the recommendations in GRADE. This would, however, have led to all evidence being downgraded in spite of its being appropriate to help to answer the research question, "*what are the predictors of care home admission following acute hospitalisation?*". As a result, a more pragmatic approach was taken, downgrading instead for the other recognised parameters which can reduce the quality of available evidence in these observational studies.

## 3.5 CONCLUSIONS

Care home admission following hospitalisation is an important outcome, particularly among older adults. Older age, female sex, dementia and functional dependency are statistically significant predictors among hospital inpatients which have clinical validity, however they are not particularly discriminatory. Other predictors relevant in clinical practice, such as the availability of social support and patient preferences, have not yet been evaluated adequately among inpatients. Heterogeneity and poor quality of reporting mean it is challenging to summarise what is known about the predictors of care home admission following hospital admission.

Key recommendations for further research include:

- use of logistic regression analysis where appropriate;
- reporting of all results irrespective of statistical significance;
- greater inclusiveness in study design to reduce selection bias;

- more consideration of likely confounding variables in this population;
- improved use of protocols of observational research to allow evaluation of reporting bias and;
- clarity among authors about the model of care provided within the outcome of interest, namely, care home admission.

Conducting this review presented challenges in identifying care home papers due to heterogeneity in terminology and definitions of care settings. Another avenue identified for further research is formulating a search filter for care home research and this will be discussed in Chapter Four.

It is imperative that any further research measures include mixed methodological approaches. This systematic review sought quantitative studies reporting numerical data on predictors. Qualitative data may help to identify predictors which are more relevant to individuals, including social support, patient preferences, finance, health and social care infrastructure. This may help with the planning of future prospective data collection to integrate variables measured routinely and those requiring bespoke data collection.

# CHAPTER FOUR

# Identifying care home research:

# Methods to develop a search filter and a survey of international researchers

## SECTION ONE: Methodology to develop a search filter

### 4.1 INTRODUCTION

The provision of care for adults who are unable to live independently varies internationally. Within this variation are different systems for providing health and social care, national policies, politics and cultural attitudes. Levels of state and private provision and finances are also highly significant factors. In spite of these differences, most countries separate the acute provision of healthcare services in hospital settings from the care of those with more chronic conditions who cannot live independently and instead require long-term care, often termed institutional care. The International Association of Gerontology and Geriatrics (IAGG) and AMDA foundation (The Society for Post-Acute and Long-Term Care Medicine), recognised this and developed an international definition for a 'nursing home', authored by international experts (Sanford *et al*., 2015). Central to that paper was a recommendation that researchers in the field must provide a description of the care and staff provided in their setting when publishing research (Sanford *et al*., 2015). This was to allow clinicians and practitioners to understand the similarities and differences in models of care reported in published research.

The terminology used in published research to describe such care settings is highly heterogeneous. In the systematic review of 53 studies described in Chapter Three, synonyms included: 'nursing home', 'residential home', 'long-term care', 'institutional care', 'assisted care', 'homes for the elderly', 'residential aged care facility', 'skilled nursing facility', 'rest home' and 'care home'. This heterogeneity represents a barrier to researchers seeking to identify all published research in this setting. There is also potential for bias if terminology used in search strategy design is orientated around local provision and understanding.

Improving information retrieval requires the development of robust search strategies and knowledge of the use of scientific databases. A study among palliative care physicians found that they identified only 25% of a sample of relevant papers when using their own approaches to searching using PubMed (Damarell and Tieman, 2016). As a consequence, the involvement of information specialists is increasingly recognised as being necessary to support those conducting evidence reviews (Lefebvre *et al*., 2013, Shenkin *et al*., 2017). Search filters are among methods which have been shown to improve the efficiency of searching compared with clinician-derived search terms alone (Shariff *et al*., 2012). Among information specialists, the search filter's principal role is to reduce the volume of information by focusing on information more likely to be relevant (Beale *et al*., 2014).

## 4.2 SEARCH FILTERS

### *4.2.1 What are search filters?*

The Scottish Intercollegiate Guidelines Network (SIGN) defines search filters as:

> *"… pre-tested strategies that identify the higher quality evidence from the vast amounts of literature indexed in the major medical databases. Filters exist for most types of experimental design and are comprised of index terms relating to study type and specific terms associated with the methodological description of good experimental design"* (Scottish Intercollegiate Guidelines Network and Health Improvement Scotland, 2017).

SIGN's main role is to identify methodologically-defined clinical evidence which is relevant to incorporate into a guideline. It therefore uses search filters to identify published literature by methodology. It has recommended filters for the identification of systematic reviews, randomised trials, observational studies, economic analyses and patient issues for use in Ovid MEDLINE, Ovid EMBASE and Ovid CINAHL (Scottish Intercollegiate Guidelines Network and Health Improvement Scotland, 2017). These filters are freely available for researchers to use and are used when SIGN searches for evidence to develop and update its guidelines. An example of a SIGN filter used in Medline is presented in **Table 4.1**.

**Table 4.1: SIGN Randomised Controlled Trial Search Filter for Medline** (Scottish Intercollegiate Guidelines Network and Health Improvement Scotland, 2017)

| |
|---|
| 1 Randomized Controlled Trials as Topic/ |
| 2 randomized controlled trial/ |
| 3 Random Allocation/ |
| 4 Double Blind Method/ |
| 5 Single Blind Method/ |
| 6 clinical trial/ |
| 7 clinical trial, phase i.pt |
| 8 clinical trial, phase ii.pt |
| 9 clinical trial, phase iii.pt |
| 10 clinical trial, phase iv.pt |
| 11 controlled clinical trial.pt |
| 12 randomized controlled trial.pt |
| 13 multicenter study.pt |
| 14 clinical trial.pt |
| 15 exp Clinical Trials as topic/ |
| 16 or/1-15 |
| 17 (clinical adj trial$).tw |
| 18 ((singl$ or doubl$ or treb$ or tripl$) adj (blind$3 or mask$3)).tw |
| 19 PLACEBOS/ |
| 20 placebo$.tw |
| 21 randomly allocated.tw |
| 22 (allocated adj2 random$).tw |
| 23 or/17-22 |
| 24 16 or 23 |
| 25 case report.tw |
| 26 letter/ |
| 27 historical article/ |
| 28 or/25-27 |
| 29 24 not 28 |

The InterTASC Information Specialists' Sub-Group (ISSG) has been formed by information specialists involved in supporting researchers across the UK who contribute evidence-based recommendations to the National Institute for Health and Care Excellence (NICE) (ISSG Search Filters Resource, 2017). This group has developed a Search Filter Resource project to *"identify, assesses and test search filters designed to retrieve research by study design or focus"* (ISSG Search Filters Resource, 2017). It has a broader definition of search filters than SIGN's:

> *"… collections of search terms designed to retrieve selections of records… records of research using a specific study design or by topic or by some other feature of the research question"* (ISSG Search Filters Resource, 2016).

The ISSG search filter resource website also provides a list of existing search filters, critical appraisal of existing filters and resources outlining potential methods to develop new search filters (ISSG Search Filters Resource, 2017).

### *4.2.2 How are search filters developed?*

One approach to developing a search filter is to review tools which might be used to evaluate the final result. This can help to identify the steps which have been recognised as important methodologically and ensure that these are incorporated into the filter design. The ISSG has created an appraisal checklist which identifies seven aspects of design and methodology which are required to ensure methodological rigour (Glanville *et al*., 2008). The components of the checklist are presented in **Table 4.2**.

**Table 4.2: UK InterTASC Information Specialists' Sub-Group Search Filter Appraisal Checklist** (Glanville *et al*., 2008)

| |
|---|
| A. Information |
| B. Identification of a gold standard of known relevant records |
| C. How did the researchers identify the search terms in their filter(s)? |
| D. Internal validity testing |
| E. External validity testing |
| F. Limitations and comparisons |
| G. Other comments |

The checklist contains a list of information and methodological issues and how these should be categorised, to help in appraising the quality of the filter (Glanville *et al*., 2008). Key considerations which the checklist highlights are: the focus of the filter (i.e. to maximise sensitivity, precision, specificity or a combination of these); how terms and gold standard sources were identified and used and; how internal and external validity were tested (Glanville *et al*., 2008). This resource can be used as a template to determine the steps needed when developing a filter to identify care homes in international literature.

A similar tool is the Canadian Agency for Drugs and Technologies in Health Critical Appraisal Instrument (CADTH CAI) which provides a summary score for each of the six domains described (Bak *et al*., 2009). Although the tool was developed for formal appraisal of published filters, its contents can again be incorporated into the study design. There is significant overlap between the CADTH CAI and the ISSG Checklist. However the CADTH CAI asks for *"… reasonable*

*justification for the sample size of the gold standard"* (Bak *et al*., 2009), a point which is not described in the ISSG Checklist.

### *4.2.3 Evaluating the performance of a search filter*

Many of the published search filters describe using a 'diagnostic tests assessment framework' to evaluate performance. The following parameters are commonly described: sensitivity, specificity, precision, accuracy and the number needed to read (NNR). These can be calculated by creating a two-by-two contingency table comparing the reference standard allocation made by the research team with the performance of the search filter (**Table 4.3**).

**Table 4.3: Two-by-two contingency table to evaluate search filter performance.** Adapted from Terwee *et al*., 2009

| **Search filter** | **Gold standard** | |
|---|---|---|
| | Article meets criteria (relevant study) | Article does not meet criteria (not relevant study) |
| Article identified | A (true positives) | B (false positives) |
| Article not identified | C (false negatives) | D (true negatives) |

The filter parameters are defined as follows (Terwee *et al*., 2009):

**Sensitivity** = A / (A + C) – proportion of all relevant records identified by the filter.

**Specificity** = D / (B + D) – proportion of irrelevant records not identified by the filter (i.e. correctly labelled as not relevant).

**Precision** (also known as positive predictive value) = A / (A + B) – proportion of relevant records out of the total number of records retrieved.

**Number needed to read** (NNR) = 1 / Precision – the number of records which need to be retrieved before a relevant record is identified.

Sensitivity and precision are the most commonly reported measures in publications of search filter performance, usually in tabular form (Harbour *et al*., 2014).

### *4.2.4 Examples of published search filters*

#### 4.2.4.1 Methodology-specific filters

Many of the existing filters which have been developed are focused on identifying specific study designs, such as randomised trials and diagnostic accuracy studies (Jenkins, 2004).

**RCTs:** Randomised controlled trials (RCTs), as core components of Cochrane reviews of interventions, have been the focus of much search filter development work (Lefebvre *et al*., 2013). These have been subject to iterations as the reporting of studies and their indexing has improved (Glanville *et al*., 2006). Those authors describe their work to improve the Cochrane

Highly Sensitive Search Strategy for RCTs (Glanville *et al*., 2006). They selected a gold standard of RCTs records and a random sample of non-trials, search terms were extracted from the RCTs where they occurred in at least 1% of records and the terms were then used to differentiate between a subset of RCTs from a subset of non-trials, using logistic regression. Terms which were most discriminatory were then validated on the remainder of the RCTs and non-trials (Glanville *et al*., 2006).

**DTA studies:** Filters to identify studies which use a diagnostic test accuracy (DTA) methodology have also been an area of research activity, leading to a 2013 Cochrane review (Beynon *et al*., 2013). Nineteen studies were included which reported on 57 MEDLINE filters and 13 from EMBASE, however none of the filters was considered to be acceptably sensitive or precise for use in isolation to identify DTA studies (Beynon *et al*., 2013). Current recommendations for conducting systematic reviews which include DTA studies are that a search strategy should be constructed using controlled vocabulary and text words and this strategy can utilise search filters (Relevo, 2012).

#### 4.2.4.2 Topic-specific filters – methods & results

Search filters to identify research on a specific topic, rather than to identify a methodology are a more recent development. The following examples of published filters provide detail on the methods used by their authors, which have been incorporated into the methodology proposed in Section 4.3.

**Automation of comparisons & external validation:** A Canadian research group has developed filters for key topics in nephrology including general renal subject material (Iansavichus *et al*., 2010), glomerular disease (Hildebrand *et al*., 2012), chronic kidney disease (Iansavichus *et al*., 2015) and acute kidney injury (Hildebrand *et al*., 2014). These filters have used the DTA framework described earlier: identifying relevant articles from journals; retrieving terms from those relevant journal articles; evaluating their sensitivity, specificity and so on as filters, using computer-based algorithms. This allowed for the comparison of thousands of potential term combinations in a more automated method. These studies then included what the authors term 'proof of concept' studies, where they asked a group of senior clinicians to evaluate the performance of their own suggested search terms against the search filters (Hildebrand *et al*., 2014, Iansavichus *et al*., 2015) as a form of external validation.

**Hand searching to develop reference set and validation set**: van de Glind *et al.* created a search filter to identify studies in the field of geriatric medicine within MEDLINE (van de Glind *et al*., 2012). Their reference set was derived from hand searching of biomedical journals to identify search terms from which they constructed search strategies (van de Glind *et al*., 2012). The filter was created by comparing the results obtained from the search strategies with those in their reference set (van de Glind *et al*., 2012). From this approach they achieved a filter with sensitivity of 94.8%, specificity of 88.7%, precision of 73%, accuracy of 90.2% and an NNR of 1.37 (van de Glind *et al*., 2012).

**Defining the focus of included material**: A search filter to identify studies of prognosis of work disability included articles within a ten-year period and set defined eligibility criteria around the design of studies and outcome measures reported (Kok *et al*., 2015). This filter was

compared with existing filters used in occupational health and had a sensitivity of 90% comprehensiveness and an NNR of 20 (Kok *et al*., 2015).

**Dealing with contemporary, non-standard terminology**: Rogers *et al.* have developed a search filter to try to identify research which included public and patient involvement (PPI) or where PPI was the subject of the research (Rogers *et al*., 2017). PPI does not have a universally agreed definition, the terminology used can vary and many databases do not have a search term or subject heading which captures PPI (Rogers *et al*., 2017). In addition to testing their filter on a test set of articles, which resulted in 98.5% sensitivity, they also evaluated its performance when used to conduct a systematic review, where sensitivity dropped to 58% (Rogers *et al*., 2017). Review of the results and adjustments to the included terms improved the sensitivity to 73% (Rogers *et al*., 2017), but this highlights the iterative nature of search filter development, particularly in a contemporary subject area.

**Alternative method to define a gold standard**: An alternative approach to hand searching journals to identify a gold standard of relevant articles is proposed by Damarell *et al.,* who created a search filter for heart failure (Damarell *et al*., 2011). Their gold standard of articles to identify terms and develop the filter were derived from articles included in a clinical practice guideline and their validation dataset included articles from that guideline which had not been used in the earlier stages together with articles included in Cochrane reviews on the topic (Damarell *et al*., 2011). Such an approach may be useful when the topic is clinically orientated and clearly defined.

**Determining the sample size for inclusion**: When Terwee *et al.* performed a sample size calculation based on the prevalence of papers on their subject of interest (measurement properties) from a sample of records from PubMed, the prevalence was found to be 1% (Terwee *et al*., 2009). They wanted to ensure that there would be sufficient relevant articles included when they used PubMed for their sample. The calculation required estimating the sensitivity they wanted their filter to achieve (98%), so they sampled 10,000 PubMed records as their gold standard. This approach was intended to represent the literature on which the filter would be tested and also helped to identify irrelevant material which they could incorporate in the filter design for exclusion using the 'Not' operator (Terwee *et al*., 2009).

### *4.2.5 Limitations of search filters*

Search filters have limitations. They can lack sensitivity, such as when trying to identify literature specific to nursing professionals, difficulties were found due to the overlapping scope of practice between nurses and other healthcare professionals (Wilczynski *et al*., 2016). Filters can lack specificity, especially in complex concepts where heterogeneous terminology is used, such as that specific to the field of knowledge translation (McKibbon *et al*., 2012). In one example, a palliative care search filter developed for use only in the general medical literature achieved a sensitivity of 56% and the precision was only 22% (Sladek *et al*., 2006). Later review of false negative results found that much of the imprecision was driven by the lack of palliative terms used in the Medical Subject Headings (MeSH) terms for these articles, making them more difficult to retrieve (Sladek *et al*., 2007). It is thus important to be aware of the limitations of any

search filter which is used (Jenkins, 2004) and to recognise that filter development may be more challenging when there is a lack of shared terminology to assist the subject heading allocation.

## 4.3 PROPOSED METHODOLOGY

The methodological approach for developing a search filter to help identify care home research will be based on the components of the InterTASC ISSG Search Filter critical appraisal checklist (Glanville *et al*., 2008), supplemented by the findings of the literature review described above. The key steps required include the following.

### *4.3.1. Identify a 'gold standard' of known relevant papers*

This will be done by identifying papers which describe care home research by hand searching journals of relevance. Papers will be classified as 'describing care home research' or 'not describing care home research'. This will be done by two researchers reviewing included articles independently. These papers will be divided into a development set and a validation set for subsequent testing.

The journals for hand searching will be chosen informed by the results of the international survey of researchers described below in Section Two of this Chapter. A sample size calculation will be performed based on estimating the prevalence of care home research in the included journals to ensure there are sufficient examples of relevant research included.

### *4.3.2. Extract indexing terms, keywords and relevant phrases*

The development set will be analysed to extract Medical Subject Headings (MeSH) terms (or equivalent indexing terms), keywords and relevant terms and phrases identified by using word frequency analysis and visualisation. This will require analysis of both relevant and irrelevant papers. This analysis will generate lists of search terms which can be tested, singly and in combination, to determine their usefulness in identifying relevant papers.

### *4.3.3. Test the performance of selected terms and develop the filter content*

For each search term, or combination of terms, a two-by-two contingency table will be created to establish how well the term performs in classifying relevant and irrelevant papers. This will be an iterative process requiring multiple (thousands) of comparisons of terms and will be done using computerised algorithms. Terms which perform well, optimising the test metrics described earlier (Section 4.2.3), will be selected for inclusion in the search filter.

### *4.3.4. Evaluate internal validity of the search filter(s)*

The internal validity of each filter will be assessed by evaluating its performance on the validation set of papers retained earlier. Relevant papers not identified by the filter and irrelevant papers included will be reviewed to see if further adjustments are needed to the filter

to optimise performance before finalising its agreed components. There are no defined levels of acceptable sensitivity or specificity. The ideal filter properties will be determined by, for example, the nature of the research question and the available time of the research team. As a result, filters will be presented which maximise sensitivity, precision and sensitivity and which can be tested in the next step.

### *4.3.5. Evaluate external validity of the search filter(s)*

Once the performance of the filter(s) has been optimised, external validity testing will include comparison between filter performance and the terms suggested by expert researchers. This can be done either by asking for researchers to suggest existing systematic reviews to test if the filter identifies the included studies and compare how the filter performs compared with the search strategy used when the review was performed. Alternatively, researchers can be asked to generate a list of search terms, comparing the performance of the filter with the terms they identified when retrieving relevant literature.

The final outcome will be to describe and share search filters in which the sensitivity, specificity, precision, accuracy and number needed to read are described. These are typically presented as a filter to maximise sensitivity, another to maximise specificity and a third which balances the two (McMaster University and Health Information Research Unit, 2016). This allows individual researchers to select the filter which best fits their need for comprehensiveness *versus*, for example, time to read. In addition to publishing the filters, they will be disseminated using relevant research networks such as the Nursing Home Research Working Group and international Geriatric Medicine Societies. Filters can then be developed for the other databases used to identify care home research including EMBASE and CINAHL, adapting the method to suit the terminology and categorisation of each database. The aim of this work will be to improve the retrieval of existing evidence in this complex, but important, population to share learning and further develop the evidence base.

# SECTION TWO: Identifying search terms and core journals: an international survey of long-term care researchers

## 4.4 BACKGROUND

Section One established that a key component in developing a search filter is to identify a "*gold standard of known relevant records*" (Glanville *et al*., 2008). Previous search filter studies have based the terms selected for inclusion by identifying relevant articles in published journals in the field through hand and electronic searching (van de Glind *et al*., 2012). This approach can also be supplemented by asking experienced researchers to provide search terms to compare with the performance of the search filters (Hildebrand *et al*., 2014, Iansavichus *et al*., 2015). To ensure that this project has international utility and generalisability, it was deemed essential to consult experts in the field across the world to identify appropriate terms.

Surveys represent a feasible and useful method for gathering information to help inform the development of research tools and guidance. Tolson *et al.* conducted an international survey of nursing homes, achieving responses from 30 countries *via* the International Association of Geriatrics and Gerontology Global Ageing Research Network (IAGG GARN) mailing list (Tolson *et al*., 2013). When specific information is sought from experts in the field, targeted approaches have been found to be an effective way of gathering it (Partridge *et al*., 2014, Mayne *et al*., 2014, Morandi *et al*., 2013). This section of the Chapter will describe the design and use of a survey of international care home researchers to gather data to inform the development of a search filter to identify care home research. Key findings from the survey have been published (Burton *et al*., 2017), the methods and results presented here are more comprehensively described.

## 4.5 AIMS

To identify search terms used to describe long-term institutional care settings and the core journals used to find relevant research for use in the development of a search filter. This search filter would be used in future when seeking published research on care homes, defined as "*settings for adults who are unable to live independently in their own homes and require care in a long-term institutional setting*".

## 4.6 METHODS

A short survey was designed and produced in both paper and electronic formats (see Appendix 4.1). The electronic version was hosted on the web-based platform Survey Monkey (Survey Monkey, 2017). Respondents were sought by three approaches:

(1) Delegates attending the Nursing Home Research International Working Group (NHRWG) Meeting 2016 in Barcelona (n=120) were invited to participate in the survey. They were provided with paper copies in delegate packs and the link for electronic completion. Announcements were made during the conference to encourage completion.

(2) The survey was emailed to members of the European Geriatric Medical Society (EUGMS) Long-Term Care (LTC) Special Interest Group (SIG) (n=57), inviting electronic completion *via* the survey link.

(3) Personalised emails, inviting electronic completion *via* the survey link, were also sent to the corresponding authors of systematic reviews published over the preceding three years and to authors of systematic review protocols (identified on PROSPERO) in long-term institutional care settings (n=103).

### *4.6.1 Survey development*

Appendix 4.1 contains the survey circulated for completion. This finalised version was developed in response to comments from supervisors, researchers in the field and lay consultation. The comments fell into three broad areas: language; design & structure and; question design.

#### 4.6.1.1 Language

In common with much scientific writing the need for consistency in the phraseology used was identified. As the survey is about heterogeneity of terminology, it was difficult to select a phrase which was sufficiently clear as to the response sought and setting described. This meant some questions appearing lengthy as the phrase "*settings for adults who are unable to live independently in their own homes and require care in a long-term institutional setting*" was repeated throughout, instead of using the more informal 'these settings'. This was to ensure a clarity of purpose to each of the questions to keep respondents focused on the question of interest.

An initial draft used terminology distinguishing those living in the community from those in care homes: "*people who are unable to live independently in the community and require care in a long-term institutional setting*". A colleague reviewing the survey pointed out that care homes can be considered to be within the community, so suggested that the phrasing should be revised.

Simpler changes included making the text more specific, i.e. referring to 'adults' rather than 'people', as our interest is in adult care homes. Instructions were shortened, simplifying sentence structure and adding more active verbs to make the survey more accessible to those for whom English is not their first language.

#### 4.6.1.2 Design & structure

Attention was paid to ensuring the paper version of the survey was clearly presented and limited to two sides of A4 paper while providing sufficient space to allow respondents to give clear answers. The online platform allowed questions to be presented over a greater number of pages. Question ordering was, however, consistent across the two formats.

One of the key challenges in design was in establishing a way to differentiate between terminology which has different meanings in different countries and healthcare settings. It was clear there is no 'right answer' and thus options inviting respondents to rank responses did not

seem appropriate. A Likert scale was chosen with five points to ensure differentiation of agreement, neutrality and disagreement with terms. Arguably, the most useful is for terms with which respondents 'disagreed', indicating that they did not represent a long-term institutional care setting in the respondents' country of practice. Some of the feedback questioned the value of having five options within the Likert scale and possible reduction to three was discussed with supervisors. It was argued, however, that five points can be compressed to three if needed and that a greater degree of variation in responses can be represented over five points.

The benefits of including multiple choice options (for country of practice for example) *versus* free-text responses were discussed. For this specific example, free text was chosen to ensure there was no bias in the ordering, inclusion or arrangement of the lists. There was, however, a need to balance multiple-choice and free-text responses. For the key question of interest – choice of search terms – a conscious decision was made to ask an open question first before providing options, to reduce the potential that respondents would only list the suggestions provided. This list was formulated based on the results of previous searches within the topic and thus carries its own potential biases. The separation of the open question from the list of responses would be more effective in the electronic form of the survey where the questions appeared on different pages.

#### 4.6.1.3 Question design

Although a question was included about the professional background of the respondent, a decision was made to remove a question aimed at gauging their level of experience. This was largely because the value of such a question in interpretation of findings on length of professional service may not be associated with familiarity in research or systematic review. This question was removed to avoid collecting data the purpose of which was less clear.

Decisions about which journals to include in the list of responses also changed as the survey developed, recognising the scope and interdisciplinary nature of care home research. Although the original intention had been to include only journals in geriatric medicine, listed by impact factor, feedback led to this being modified to include journals from nursing and social sciences. There is potential for bias from the selection included, however these were to be indicative for the next stage and the search filter development will not be limited to the responses found here.

The question regarding databases was also modified, with a clearer focus on the information required from the survey. Most reviewers would use multiple databases and so simply listing the databases used was felt to be of limited value. Given the differences in indexing between the databases, it was recognised that selecting which database is used most frequently would be helpful in prioritising which database might be the focus for the search filter created.

The question relating to the perceived usefulness of a search filter was prioritised to be the third, rather than the final, question. Links were provided to the simple definition of a search filter to help ensure respondents understood what was being asked.

Consideration was given to the role of including deliberately incorrect options within the list, for example, 'hospital' or similar. As the aim of this survey is to identify useful terms and terms which lack international recognition or use to help inform the search filter design, not to test the

knowledge of respondents, particularly when inviting so much international support, including incorrect options only offered the potential to cause confusion to no good purpose.

Although keen to acknowledge the contribution of all survey respondents formally, privacy was respected by having completion of the questions relating to name, email address and further contact all voluntary.

The final challenge was to formulate brief introductory text for participants. This needed to be as clear and simple as possible, while also explaining the issue being studied and purpose of the survey. A key consideration was to ensure this work was defined as being distinct from the consensus exercise to define 'nursing home' (Sanford *et al*., 2015). Eventually this was stated explicitly, formally acknowledging this previous work and explaining how the present survey differed in scope and purpose.

### *4.6.2 Data collection*

Data were collected on:

- Country of practice
- Field of primary professional qualification
- Perceived usefulness of a search filter
- Previous involvement in systematic review/original research in this setting and terms used
- Extent of agreement with list of identified search terms
- Free text for additional terms
- Journals used to identify published research
- Identification of most commonly used database for this topic

Although completion was voluntary, all participants were asked for their name and organisation affiliation to allow them to be acknowledged. No other sensitive material was requested and the nature of the data collected represent professional opinions, unrelated to specific aspects of patient care or management.

### *4.6.3 Data analysis*

Data were extracted on the respondent's country of practice, evaluating the terms, journals and data sources provided. Data from both paper and electronic completion were entered into IBM SPSS Statistics Version 22. For analysis, the Likert scale was dichotomised into agreement (combining strongly agree and agree) *versus* disagreement (combining disagree and strongly disagree). Where more than two-thirds of responses were in either category this was considered 'good' agreement or disagreement. Responses from individual countries were compared when more than ten were received. Voyant Tools (Sinclair and Rockwell, 2017) freeware was used to perform word frequency analysis and create a pictorial summary of terms suggested by respondents.

### *4.6.4 Ethical approval*

The NHS Research Ethics and Research and Development (R&D) departments were contacted and confirmed that no submission for ethical or R&D approval was required to distribute and analyse this survey.

## 4.7 RESULTS

105 responses were received, 47 (45%) were completed on paper and 58 (55%) were completed online. This represents a response rate of 38% of the 280 invited to participate (NHRWG n=120; EUGMS LTC SIG n=57; systematic review or systematic review protocol authors n=103). This is likely to be an under-estimate, however, as there is significant overlap in the conference attendees and membership of the EUGMS LTC SIG.

### *4.7.1 Respondent characteristics*

Responses were received from 21 countries in total (**Table 4.4**). Responses from the UK, The Netherlands and Australia account for just under half of all received.

Most respondents had their primary professional qualification in medicine and a fifth of responses were from nurses (**Table 4.5**).

**Table 4.4: Country of practice of respondents**

| Country | N (%) | Country | N (%) |
|---|---|---|---|
| UK | 21 (20) | Austria | 2 (1.9) |
| The Netherlands | 17 (16.2) | France | 2 (1.9) |
| Australia | 13 (12.4) | Iceland | 2 (1.9) |
| USA | 10 (9.5) | Poland | 2 (1.9) |
| Germany | 7 (6.7) | Turkey | 2 (1.9) |
| Canada | 5 (4.8) | Indonesia | 1 (1.0) |
| Belgium | 4 (3.8) | Malta | 1 (1.0) |
| Norway | 4 (3.8) | Portugal | 1 (1.0) |
| Ireland | 3 (2.9) | Slovenia | 1 (1.0) |
| Italy | 3 (2.9) | Sweden | 1 (1.0) |
| Spain | 3 (2.9) | | |
| **Total N = 105** | | | |

**Table 4.5: Professional discipline of respondents**

| Discipline | N (%) |
|---|---|
| Medicine | 39 (37.1) |
| Nursing | 20 (19) |
| Social sciences | 17 (16.2) |
| Therapists (Physiotherapy, Allied Health Professionals) | 7 (6.7) |
| Psychology | 4 (3.8) |
| Nutrition | 3 (2.9) |
| Health Sciences | 3 (2.9) |
| Pharmacy | 2 (1.9) |
| Other (Systematic reviews, Business Administration, Health, Exercise Science, Lawyer, Manager, Information Specialist, Epidemiology, Social Work) | 9 (8.7) |
| | **Total N = 104*** |

**Not all respondents completing paper surveys responded to each term, online response was mandatory for each item.*

82 respondents (78%) had previous experience of conducting a systematic review and/or original research in settings for adults who are unable to live independently in their own homes and require care in a long-term institutional setting.

Most respondents stated that a search filter would be useful to help to identify research about settings for adults who are unable to live independently in their own homes and require care in a long-term institutional setting. They included 55 (52.4%) who considered it 'very useful', 43 (41%) who considered it 'useful', five (4.8%) who responded as 'neutral' and two (1.9%) who responded that it was 'unnecessary'.

### *4.7.2 Terms used to identify or describe long-term institutional care settings in previous reviews*

83 respondents (79%) answered this question – six of these provided links to specific search strategies or reviews they have conducted or offered to share search strategies by email. 72 (87%) provided lists of search terms of words they have used in their searches.

After removing those which were topic-specific (e.g. palliative, hospice) to retain only those relevant to settings for long-term institutional care, a total of 1,175 words remained. These were analysed using the Voyant software to generate word frequencies and a pictorial summary (**Figure 4.1**). The most commonly-used word was 'care' (170), followed by 'home' (109), 'nursing' (92), 'long' (67) and 'term' (67).

**Figure 4.1: Pictorial summary of words used in search terms**


### *4.7.3 Search terms*

Respondents were asked to indicate their level of agreement with the specified terms in their own country of practice to identify care long-term institutional care settings (**Table 4.6**).

**Table 4.6: Likert scale responses for search terms, ranked based on agreement**

| Search term | Strongly agree | Agree | Neutral | Disagree | Strongly disagree | Responses N* |
|---|---|---|---|---|---|---|
| Nursing Home | 83 | 17 | 2 | 1 | 1 | 104 |
| Long-term Care | 58 | 28 | 10 | 6 | 0 | 102 |
| Care Home | 44 | 31 | 10 | 16 | 3 | 104 |
| Residential Home | 27 | 43 | 14 | 15 | 2 | 101 |
| Residential Facility | 25 | 43 | 22 | 12 | 0 | 102 |
| Institutional Care | 24 | 35 | 17 | 24 | 3 | 103 |
| Skilled Nursing Facility | 24 | 22 | 17 | 31 | 9 | 103 |
| Institutionalisation | 19 | 30 | 20 | 23 | 11 | 103 |
| Care Facility | 16 | 42 | 20 | 22 | 3 | 103 |
| Homes for the Aged | 14 | 35 | 16 | 28 | 8 | 101 |
| Continuing Care | 10 | 23 | 27 | 34 | 9 | 103 |
| Sub-acute Care | 7 | 9 | 23 | 49 | 15 | 103 |
| Transitional Care | 6 | 20 | 23 | 40 | 14 | 103 |
| Post-acute Care | 6 | 18 | 20 | 45 | 14 | 103 |
| Medical Home | 2 | 7 | 15 | 55 | 24 | 103 |

**Not all respondents completing paper surveys responded to each term, online response was mandatory for each item.*

Additional comments were provided by 25 participants (24%) to accompany their responses to the question. These have been grouped in the table below to reflect where guidance is country-specific or related to language (**Table 4.7**).

### Table 4.7: Additional comments on terminology

**Australia**
"In Australia "transitional care" is a temporary care setting following discharge from hospital"
"In Australia our government changed the term to Residential Aged Care Facility"
"The formal terminology used by Government departments in Australia is "Residential Aged Care Services (RACS)", this includes what were formerly referred to as nursing homes and aged care hostels."

**Canada**
"Here in Ontario we have 3 levels of care 1- retirement home 2- nursing home or long term care or long term nursing home or continuing care all are the same : patient need close care 3- home care : clients staying in their own homes and they have nurses and nursing assistance (PSW) who are coming to take care about them 24/7"
"In my province of Canada (Ontario) we have different levels of care for older adults: Some may manage in a retirement home (usually has very upscale and expensive apartments and minimal nursing care); others would live in long term care homes where there is more nursing care. Some may go to a transitional care bed in a long term care home or retirement home funded for that purpose while waiting for a long term care bed so as not to take up a much sought-after hospital bed. Still others require complex continuing care in a hospital setting-more nursing care than received in long term care, but less than an acute care hospital--might be referred to post-acute or sub-acute care."

**Ireland**
"In Ireland, there is a distinction between 'nursing homes' and 'step down facilities'. Step down facilities are for older people transitioning from acute care to long-term care or nursing homes. They are to move people out of acute care, as they no longer require acute medical care, but cannot return home and are waiting on a nursing home bed in a long-term care (LTC) facility. I had assumed that you are specifically concerned with nursing home care as LTC and not transitional care in step down facilities - though perhaps such facilities are unique to Ireland? Or in other areas these facilities are also regarded as a LTC? Are post-acute care and sub-acute care also such step down facilities?"
"Nursing Home is by far the most commonly used term in Ireland"

**The Netherlands**
"There are no 'residential care homes' anymore (in the Netherlands)"

**Poland**
"We have two types of LTC facilities: one rendered in the frame of health care sector - with doctor and registered nurses onsite for 24/7 - these are nursing homes (literally translated into English: Care & Treatment Facility) with nurses 24/7 and doctors employed 2-5 times a week (not for night duties) (called Nursing & Care Facility). The other group of facilities with different funding and organization are residential homes (for older people, for chronically ill persons, for chronically psychiatric ill persons, for physically disabled and for intellectually disabled). They are organized in frame of social care sector. We call them residential because residents stay there forever, until their death. So these homes are like real home for them. However in most of the facilities only care-assistants provide care 24/7, offsite nurses come there to provide nursing care only during day shift; and doctors (GP) are available on call, only - they are not employed by the facility, they provide care based on contract with Health Fund as for the other people living in the community."

**Slovenia**
"In our country the "official" name for such facilities is "Home for the Aged"."

*Table 4.7 continued overleaf*

***Table 4.7 continued***

| |
|---|
| **UK**<br>"Long term care can mean either care home or hospital based care, so would need to be included in UK search term, but may not be relevant"<br><br>**USA**<br>"In the US is there is a spectrum of residential facilities for those who need assistance with at least one activity of daily living. There is a distinction between those with nurses on staff (nursing in the name) and those that do not provide medical/nursing care (i.e., assisted living facility)"<br>"There is a difference in the US between transitional care, rehabilitation, sub-acute and post-acute and long-term care services. Sometimes the facilities are the same, but the goals and care is different between short-term sub-acute and long-term residential care"<br>"Transitional care is less than 60 days. Post-Acute applies to both home and long-term nursing homes"<br><br>**Language**<br>"I detest the term 'institutionalised' as I feel it has serious negative connotations. My preference is 'long-term care' as I feel this can encompass both social and hospital settings."<br>"I personally do not endorse the use of the word 'facility' as it is depersonalising. Preference is for care home."<br>"Residential facility' has a different connotation" |

18 respondents also added the following additional terms which they felt should be included in a search strategy (**Table 4.8**).

**Table 4.8: Terms not included in survey which respondents perceived as relevant**

| |
|---|
| "Aged care (common in Australia) Veteran (common in USA)" |
| "Assisted living, memory facility" |
| "Elderly care, geriatric care" |
| "Extra care; specific terms relevant to demonstration projects (e.g. greenhouse)"<br>"SNF (skilled nursing facility) which provides more medical care by nurses and doctors onsite (employed by facility), funded by health care system and aiming to absorb patients from hospitals to improve their physical health to be able to return home.<br>Non-SNF (non-skilled nursing facility), which is focused on personal care provided by care-assistants for residents, who stay there forever. Nurses and doctors are on call.<br>LTCF-long term care facility - is more general including all types of institutions providing LTC" |
| "Housing with care, dementia care"<br>"In Australia, "residential aged care", "residential aged care facility", "RAC", "RACF", "low level care", "hostel", "high level care""" |
| "Medical geriatric unit" |
| "Perhaps "assisted living facility", depending on what you are trying to define" |
| "Post-acute rehabilitation" |
| "Residential aged care facility RACF or residential aged care RAC" |
| "Residential Aged Care Facility, Community Hospital" |
| "Residential aged care services" |
| "Residential aged care, assisted living facility" |
| "Residential care residential aged care facility"<br>"Retirement home"<br>"Senior home; Home of a peaceful ageing" |

The additional terms in **Table 4.8** and the narrative responses in **Table 4.7** indicate that there are other terms which are particularly relevant in specific countries and confirm that all terms do not have the same meaning internationally.

Comparison was made between the four countries which provided ten or more respondents, to try to identify any patterns or variation in terminology (**Table 4.9**).

**Table 4.9: Comparison of terms by country of response**

| Country (nº of responses) | Terms with good agreement | Terms with disagreement |
|---|---|---|
| Australia (n=13) | Care facility, home for the aged, nursing home, residential facility, residential home | Medical home, post-acute care, sub-acute care, transitional care |
| The Netherlands (n=17) | Care home, care facility, institutional care, long-term care, nursing home | Medical home |
| United Kingdom (n=20) | Care home, long-term care, nursing home, residential facility, residential home | Medical home, sub-acute care |
| USA (n=10) | Long-term care, nursing home, skilled nursing facility | |

### *4.7.4 Journal choice*

Respondents were asked which journals they consult to identify research relevant to settings for adults who are unable to live independently in their own homes and require care in a long-term institutional setting. From the list of journals provided for respondents, **Table 4.10** summarises their use.

**Table 4.10: Journal use reported by respondents**

| Journal | N (%) | Journal | N (%) |
|---|---|---|---|
| Age and Ageing | 74 (70.5) | Journal of Nursing Home Research | 33 (31.4) |
| Journal of the American Medical Directors Association | 71 (67.6) | Ageing and Society | 27 (25.7) |
| Journal of the American Geriatrics Society | 71 (67.6) | Palliative Medicine | 27 (25.7) |
| Journals of Gerontology Series A | 41 (39) | Ageing Research Reviews | 23 (21.9) |
| American Journal of Geriatric Psychiatry | 37 (35.2) | Scandinavian Journal of Caring Sciences | 17 (16.2) |
| International Journal of Nursing Studies | 35 (33.3) | Aging & Disease | 12 (11.4) |
| International Journal of Geriatric Psychiatry | 34 (32.4) | Maturitas | 12 (11.4) |
| **None of the above** | | **5 (4.8)** | |

Seven respondents stated that they do not refer to specific journals, but would identify relevant literature *via* databases. In total, 47 additional journals were suggested by respondents, 17 of which were mentioned by two or more respondents (**Table 4.11**).

**Table 4.11: Additional journals suggested in free text**

| Journal | N | Journal | N |
|---|---|---|---|
| BMC Geriatrics | 5 | Archives of Gerontology and Geriatrics | 2 |
| European Geriatric Medicine | 5 | BMJ | 2 |
| International Psychogeriatrics | 5 | Dementia | 2 |
| International Journal of Older People Nursing | 4 | Drugs and Ageing | 2 |
| Journal of Advanced Nursing | 4 | Geriatric Nursing | 2 |
| Journal of Nutrition Health & Aging | 4 | Geriatrics and Gerontology International | 2 |
| The Gerontologist | 4 | Journal of Clinical Nursing | 2 |
| Ageing and Mental Health | 3 | Journal of Gerontology Series B | 2 |
| Zeitschrift für Geriatrie und Gerontologie | 3 | | |

### *4.7.5 Database selection*

Respondents were asked to choose between the three main databases used in the medical literature, indicating which they would use first, to help determine the database for which the filter should be designed. The majority (85/96 88.5%) selected MEDLINE/PubMED, followed by CINAHL (8/96, 8.3%) and EMBASE (3/96, 3.1%). The reduced number of responses (96/105) reflects individuals making more than one selection.

### *4.7.6 Acknowledgement and further participation*

81 respondents (77%) provided their names and institutions, allowing their contribution to be acknowledged formally and 80 of these also provided email contact details and indicated that they would be agreeable to being contacted further in the development phases of the search filter project.

## 4.8 DISCUSSION

### *4.8.1 Findings*

A short targeted survey of researchers and practitioners received good engagement and has generated useful data to inform the development of the search filter and to help those searching the literature. Analysis of the findings confirms that there is considerable international variation in terminology used to describe long-term care settings. Furthermore, it indicates the complexities in interpreting words or phrases without an accompanying description of the care provided in that setting. It may be that the extent of variation in meaning of the same words internationally means that search filters may need to be adapted, based on the country or region of interest. The search filter project must evaluate the sensitivity and specificity of terms and results to determine the optimal combination.

A list of relevant journals was generated which are likely to identify examples of research in this field to allow development of a 'gold standard' set of relevant and irrelevant research. A search filter was considered a useful development by a significant majority of respondents with a preference for MEDLINE/PubMED identified in the first instance. A willingness for involvement in this work was expressed by more than three-quarters of respondents.

Only five terms were identified with more than two-thirds agreement from all respondents – 'care home', 'long-term care', 'nursing home', 'residential home' and 'residential facility'. 'Care home' had good agreement in the UK and The Netherlands, but not in the USA or Australia. 'Residential facility' and 'residential home' had good agreement in Australia and the UK but not in the other two countries. 'Homes for the Aged', a MeSH term commonly applied to long-term care literature, had good agreement in respondents from Australia, but was only identified by fewer than half of all survey respondents.

One term ('medical home') had poor agreement among all respondents and this was consistent across the four countries where responses were examined in detail. Terms such as 'continuing care', 'post-acute care', 'sub-acute care' and 'transitional care' had the greatest international variation in response.

### *4.8.2 Strengths and limitations*

The survey was short and well-completed. Respondents offered additional material and seemed to be willing to share their experiences and, in some cases, data to assist. The information provided augments the body of knowledge required to inform the search filter design.

Although a fifth of responses originated from the UK, The Netherlands, Australia and the USA also provided significant contributions. The spread of responses did not allow for other countries to be analysed in detail. Data from Asia were limited and no responses were received from Africa or South America. These countries have nursing homes from where survey responses have been received previously (Tolson *et al*., 2013), thus the present findings may not be applicable to researchers there. The response here, however, maps to the international representation in the published English language research literature in long-term care to date, identified in a previous systematic mapping review (Gordon *et al*., 2012). One way to broaden the relevance of the work would be to identify geriatric medicine societies or research centres in the countries not currently represented and ask them for suggested terminology and journals. While engagement from healthcare professionals was good, we had only limited absolute numbers of responses from those in social care, who are crucial in delivery of care in many countries.

Several approaches were used to find relevant participants: those expressing topic-specific interest by attendance at the NHRWG meeting; those with special interest in the field *via* the EUGMS LTC SIG and; those with review experience as authors of reviews or protocols. This recruitment strategy was designed to ensure a range of representation of views and countries included. It is recognised that not all of the respondents had expertise in systematic reviewing and some of the free-text comments indicate that some provided responses based on terminology preferences, rather than search terms. The search conducted to identify reviews in long-term care introduces the bias associated with existing knowledge of relevant search terms and understanding of this field. The enthusiasm and interest of those responding may be affected by responder bias, given the detail required to complete the survey.

Although the survey was piloted before use, some respondents in the pilot had English as a second language and this may have affected its general applicability. It was difficult to balance

the clarity of question design with the need for completeness and specificity of the question to the subject matter.

Finally, the threshold chosen for agreement/disagreement of more than two-thirds was not pre-specified, but selected during analysis of the data. This has the potential to introduce bias in the interpretation of the findings as the process was not independent. It would have been preferable to define how the data collected should be analysed before review of the results was undertaken.

### *4.8.3 Alternative approaches*

The survey sought to explore terminology by inviting respondents to agree or disagree with a selection of terms and providing space for them to add additional terms or clarification on meaning in their country of practice. Alternative novel ways of identifying relevant terms include the use of text mining techniques and natural language processing.

Text mining is a process which aims to extract new information from unstructured text by identifying patterns (Hearst, 1999). Such approaches have been used in systematic reviewing to help manage the task of screening the ever-growing scientific literature for potentially relevant material (Thomas *et al*., 2011). They can help to reduce the time to perform a review by recognition and highlighting of relevant terms (Thomas *et al*., 2011). PubMed PubReminer (Koster, 2014) and MeSHOnDemand (NIH US National Library of Medicine, 2016) are two freely-available text mining software tools which perform word frequency analyses and identify Medical Subject Headings (MeSH) terms which may be used in designing a search strategy. These can both be useful if the terminology is known or predictable and the author is looking for synonyms. If a sample of relevant papers is available, visual text mining approaches using online freeware, VosViewer (Centre for Science and Technology Studies Leiden University, 2017) can also be helpful in identifying relationships between words and phrases and identifying search terms, similar to that seen in **Figure 4.1**. These approaches are likely to be helpful in the next phase of this work to develop the search filter, but could not overcome the initial challenge faced, as they rely on a shared understanding of appropriate and relevant terminology.

A systematic review of the application of text mining in systematic reviews found that several approaches have been described, including using text mining to prioritise items for screening and also to replace a second reviewer (O'Mara-Eves *et al*., 2015). Many of these methods have not been replicated however and the reduced workload overall may also result in a loss of relevant studies (O'Mara-Eves *et al*., 2015). Text mining approaches are anticipated to have a greater role in the design of search strategies and, potentially, search filters to improve the efficient retrieval of information (Lefebvre *et al*., 2013).

Natural language processing (NLP) is the term used to describe a range of methods which can be used to analyse unstructured text, some of which are based on identifying the included words, others on the underlying linguistic properties of the text (Friedman and Elhadad, 2014). NLP approaches are intended to help find the underlying meaning from within a longer text and although originally performed manually, much of the field now uses statistical computational approaches (Nadkarni *et al*., 2011). One specific methodology within NLP is that of semantic analysis. Semantics: *"… concerns the meaning or interpretation of words, phrases and sentences,*

*generally associated with real-word applications*" (Friedman and Elhadad, 2014). Semantic analysis is the process by which words or phrases with a specific meaning are mapped to an associated code and the multiple uses of the word or phrase can then be evaluated and processes of identification refined to select only relevant uses (Friedman and Elhadad, 2014). This can help to identify the ways the words are used and what they mean within longer documents, such as health records, where retrieval of relevant information is otherwise laborious.

Identifying where and how authors use terminology to describe long-term care settings will be useful. Use of these more advanced techniques would not, however, have addressed the potentially UK-centric bias of testing these approaches in literature considered to describe long-term care settings. The data generated by the survey have helped to develop a better understanding of current and acceptable terms across the range of countries represented.

## 4.9 CONCLUSIONS

Section One of this chapter presented the rationale for search filters and methodology for their development. Developing a search filter for identifying care home research will not be included in this thesis as this project requires funding to support additional technical expertise. Identifying suitable funding is a priority to progress this work.

Section Two contains the results of the important preparatory work for the wider project. It established the heterogeneity in terminology used to describe care home settings, indicated useful terms and journals to search and indicated support from the international research community for the utility of such a search filter.

# PART TWO

# Exploring Current Clinical Practice

**Chapter Five**
New Institutionalisation following Acute Hospital Admission: A Retrospective Cohort Study

**Chapter Six**
One Chance to Get it Right: Exploring Perspectives and Experiences in Care Home Discharge Decision-Making

# CHAPTER FIVE

# New institutionalisation following acute hospital admission: A retrospective cohort study

## 5.1 INTRODUCTION

This Chapter describes the characteristics and documented experiences of individuals undergoing the transition from independent living in the community into a care home following an acute hospital admission. Review of the literature identified this transition as a gap in published research (Chapter One, Section 1.8.2). This Chapter reports the findings of a retrospective cohort study of 100 individuals discharged directly to a care home following an unscheduled admission to a single hospital. This work has been published (Harrison *et al*., 2017a) and the text in Sections 5.2 – 5.5 below is from the published paper with minor alterations. I analysed the results, wrote the first draft of the paper and led the collation of comments and revisions. The published paper incorporated here is followed by a wider discussion of the issues raised (Section 5.6).

## 5.2 BACKGROUND

Care home admission, often termed institutionalisation, is a significant life event for an older person which is often portrayed negatively (Alzheimer's Society, 2013). In the UK, approximately 4% of the population over 65 years (~ 400,000 people) and around 20% of the population aged over 85 years reside in care homes (British Geriatrics Society, 2011). The definition of care homes varies between countries: in the UK most places (e.g. 95% in Scotland) are occupied by long-stay residents, not expected to return to independent living in the community (Information Services Division Scotland and NHS National Services Scotland, 2015). Although this transition may have negative practical and emotional impacts on the individual (Wilson, 1997), it is often necessary for some older adults, particularly those with dementia (Verbeek *et al*., 2012).

In the UK, new institutionalisation occurs mostly through two routes: (i) community: from the patient's usual residence, or (ii) hospital: directly following an admission. Across England there is a six-fold variation in the likelihood of being transferred directly from the acute hospital into long-term care settings (Oliver *et al*., 2014). In Scotland, 47% of new long-term admissions come directly from hospital settings (Information Services Division Scotland and NHS National Services Scotland, 2015), although it is not known how many of these are from acute hospitals. Both NHS England and the Scottish Government policy argue that care home admission from acute hospitals should be avoided (NHS England, 2014, Audit Scotland, 2014). In the community, transitions generally occur as a result of decisions made by the patient, their families and health and social care practitioners based on knowledge of the long-term health and functional status of the patient. Functional impairment, cognitive impairment and dementia are among the factors which predict institutionalisation (Luppa *et al*., 2010, Luppa *et al*., 2012). Studies have documented the process and experiences of those with dementia moving to a care

home from community settings (Verbeek *et al*., 2015, Bleijlevens *et al*., 2015, Beerens *et al*., 2015).

The processes involved in new institutionalisation following acute hospitalisation are poorly researched: and no studies were found evaluating this. This is an important knowledge gap, given that >6,200 older adults experience such transitions every year in Scotland alone (Information Services Division Scotland and NHS National Services Scotland, 2015). Several reasons can be suggested for a need for a higher level of care than can be provided in the community following acute hospital admission: the presenting medical problem (Bourdel-Marchasson *et al*., 2004) or worsening of existing chronic disease; the breakdown of social circumstances and support. Additionally, hospital admission can be associated with a decline in activities of daily living, functioning and independence (Covinsky *et al*., 2003, Hoogerduijn *et al*., 2012), potentially necessitating institutional care. Although these may be valid reasons for institutionalisation, some of these factors may be transient, and the considerable variability in rates of institutionalisation from hospital (Oliver *et al*., 2014) suggest variability in decision-making processes and in turn this implies that some care home transitions may be unnecessary. Some have even argued that an admission to the acute hospital may lead to premature institutionalisation (Alzheimer's Society, 2011).

Our aim was to explore the patient characteristics, assessment processes and reasons involved in discharge to a care home following an acute hospital admission to a single large Scottish university hospital.

## 5.3 METHODS

A retrospective case-note review was conducted of patients admitted from home to a large Scottish university hospital between November 2013 and February 2015 and discharged to a care home. Inclusion criteria were: adult patients (aged ≥18 years); admitted from a private residence; discharged to a care home without returning to their previous address. A consecutive series was sought and notes were accessed until n=100 in the study cohort. The case notes were accessed at least three months after discharge to care home, incorporating those discharged from local specialist rehabilitation facilities. This was to allow time for the notes to be returned to Medical Records following discharge documentation being finalised.

The sample was identified using the electronic patient management system (TRAK) using discharge destination codes. The patients' TRAK electronic records and ward-based case notes were obtained and examined. The ward-based case notes included all medical, nursing and allied health professionals' documentation and any documentation made on the ward by additional teams, such as social workers. The Social Work records are stored on a separate electronic social care system and were not included.

The Research Nurse (RN) evaluated all case notes against the study inclusion criteria. Cases were excluded if clinical coding incorrectly identified existing care home residents or individuals not discharged to a care home. Any patient re-admitted during the project data collection phase was excluded to allow clinical use of the case notes. These were grouped with other notes which could not be accessed for the research and classified as 'unavailable records'. Finally, as our aim was to explore the assessment processes and discharge planning it was

necessary for case notes to be complete, without periods of admission missing from the record. If significant gaps were identified without documentation, typically >1 week in duration, these were excluded and classified as 'missing data'. This approach was discussed with the wider research team and agreed as appropriate. Exclusion was driven by incomplete data.

The research team (including consultant geriatricians, nurses, qualitative and quantitative researchers) developed and piloted a data collection form (Appendix 5.1). This was an iterative process to determine the variables to be included and the format for recording. The form was piloted by the RN and other members of the research team to support initial training and quality control. All data were extracted by a single RN onto the form, removing any identifiable data. A second researcher independently extracted data from a sample of case notes and their findings were compared with those of the RN to ensure consistency of approach.

### *5.3.1 Cognitive status*

An inclusive and pragmatic approach was taken in classifying cognitive status and handling overlap. Detailed case definitions are included in Supplementary Data file (Appendix 5.2). If an individual received a new diagnosis of dementia during their stay, they were analysed in this group, even if they had a history of cognitive impairment. Delirium was assessed separately in view of the potential for this to fluctuate and improve.

### *5.3.2 Ethics*

The National Research Ethics Service approved the study (REC 14/44/1092), confirming that informed consent was not required from included participants. Caldicott Guardianship Approval (a UK system to protect patient information) (Health & Social Care Information Centre, 2015) was granted.

### *5.3.3 Statistical analysis*

Data were entered into IBM SPSS Statistics, version 21 independently by myself and the RN and used for analysis. Categorical variables were presented as frequencies and percentages with continuous variables presented as means with standard deviation (SD) or medians with ranges where data were not normally distributed.

## 5.4 RESULTS

### *5.4.1 Cohort identification*

To obtain a sample of 100 discharges, 273 case notes had to be evaluated. This resulted from incorrect coding (n=44) of admission location or discharge destination, unavailability of case notes (n=33; nine cases notes had been destroyed) and missing data (n=96; 10 cases entire admission missing from notes).

### *5.4.2 Description of the cohort*

The sample (**Table 5.1**) were older adults (median 83.5 years; range 61-101), predominantly female (62%), living alone (67%), with a state-supported care package (73%). 37% had a history of recurrent hospital admissions.

### *5.4.3 Circumstances of admission*

All participants had an emergency rather than elective admission to hospital. Most were admitted under medicine (88%), with smaller numbers under orthopaedics (7%), surgery (4%) and joint care (1%). Admission reasons were recorded based on presenting complaints rather than diagnoses, so individuals often had multiple recorded reasons. Common reasons were: falls (57%); confusion (52%); sepsis (31%); neurological symptoms of stroke/TIA/seizure (14%); fractures (10%) and reduced mobility (8%).

**Table 5.1: Full description of the cohort**

| Variable | N (%) | Variable | N (%) |
|---|---|---|---|
| Female sex | **62 (62)** | | |
| **Marital status** | | **Family support**** | 92 (92) |
| Widowed | 46 (52) | Children/children-in-law | 102 (71) |
| Married | 26 (30) | Spouse/partner | 21 (15) |
| Single | 9 (10) | Niece/nephew | 13 (9) |
| Divorced/separated | 7 (8) | Other | 7 (5) |
| Missing data | 12 | | |
| **Cognitive diagnoses** | | **Type of informal care provided** | |
| Cognitive impairment* | 20 (42) | Shopping | 62 (24) |
| Diagnosis of dementia AND/OR cognitive enhancers | 55 (55) | Visiting/social | 61 (23) |
| *Subtype recorded (n=52)* | | Cleaning | 54 (21) |
| Alzheimer's disease | 17 (33) | Food preparation | 40 (15) |
| Vascular dementia | 12 (25) | Phone calls | 22 (8) |
| Lewy body disease/Parkinson's disease-associated | 4 (8) | Personal hygiene | 11 (4) |
| Not specified | 15 (29) | Dressing | 9 (3) |
| | | Other | 4 (2) |
| | | Missing data | 13 |
| **Past medical history** | | **Frequency of support** | |
| Alcohol excess | 10 (10) | Four times/day | 5 (7) |
| Falls | 63 (63) | Overnight | 6 (8) |
| Depression | 14 (14) | Daily | 40 (57) |
| Recent previous admissions | 37 (37) | Weekly | 12 (17) |
| **Prescribing** | | Monthly | 3 (4) |
| Regular prescriptions | Median of 8 [Range 0-21] | Missing data | 32 |
| Anti-psychotic use | 17 (17) | | |
| Cognitive enhancers | 28 (28) | | |
| **Functional status** | | **State package of care** | 73 (73) |
| **Mobility** | | **Frequency** | |
| Zimmer frame | 35 (35) | Seven days/week | 68 (93) |
| Stick | 27 (27) | Four times/day | 28 (38) |
| Unaided | 27 (27) | Three times/day | 15 (21) |
| Other | 11 (11) | Twice daily | 18 (25) |
| **Continence** | | Once daily | 9 (12) |
| Fully continent | 7 (62) | Other | 3 (4) |
| Incontinent of urine | 31 (33) | | |
| Doubly incontinent | 4 (4) | **Nature of support** | |
| Missing data | 8 | Personal hygiene | 60 (82) |
| **Use of continence aids** | | Medication prompting | 47 (64) |
| Continence pads | 37 (40) | Meal preparation | 52 (71) |
| Catheter | 10 (11) | | |

*Table 5.1 continued overleaf*

***Table 5.1 continued***

| | | | |
|---|---|---|---|
| **Social situation** | | **Informal/unpaid** | 10(16) |
| **Living arrangements** | | Friend | 6(10) |
| Lives alone | 67 (67) | Neighbour | 2(3) |
| Lives with spouse/partner | 25 (25) | Other | 2 (3) |
| Lives with son/daughter | 8 (8) | Missing data | 39 |
| **Housebound** | 14 (16) | | |
| **Missing data** | 12 | | |
| | | **Other formal services** | 14 (25) |
| **Type of property** | | Day centre | 7 |
| House | 37 (42) | Other (inc private carers) | 7 |
| Flat | 24 (27) | Missing data | 44 |
| Bungalow | 13 (15) | | |
| Sheltered accommodation | 11 (12) | | |
| Other | 4(4) | | |

*Footnotes: Total sample is 100 therefore where data are complete, n = %. Where n is not equal to the % this represents data which were not available or not applicable.*

**Not possible to have diagnosis of dementia and cognitive impairment simultaneously so cognitive impairment result based on proportion without dementia*

*** A total of 143 individuals were supporting 92 individuals; percentage represents proportion with at least one person in that category of relationship*

### *5.4.4 Cognitive disorders*

The prevalence of all cognitive disorders was high (**Table 5.2**). Only five individuals had no formal diagnosis of cognitive impairment or evidence of impairment on cognitive testing. Formal cognitive assessment was attempted and recorded at least once in 77% of participants. The prevalence of cognitive impairment on formal testing was high (>80%), although detailed cognitive assessments were seldom used (**Table 5.3**).

**Table 5.2: Cognitive test results at any time during hospital admission**

| Cognitive Test Data | Abbreviated Mental Test Score (AMT) N=64 | Mini-Mental State Examination (MMSE) N=36 | Addenbrooke's Cognitive Examination – III (ACE-III) N=7 |
|---|---|---|---|
| Mean [SD] | 4.8 [3.8] | 16.7 [5.4] | 52 [11.6] |
| Median | 5 | 16.5 | 56 |
| Cut-off used | 8 or lower | 23 or lower | < 82 |
| Cognitive impairment (%) | 53 (83) | 31 (86) | 7 (100) |

*Footnotes: 25/64 who had an AMT 10 also had an MMSE and 5/64 had an ACE-III.*

*3/36 who had an MMSE also had an AMT.*

**Table 5.3: Cognitive disorders**

| Cognitive Disorders | | Nº of cases/100 |
|---|---|---|
| **Dementia & Cognitive Impairment** | Known dementia | 56 |
| | Known cognitive impairment | 16 |
| | New diagnosis of dementia or cognitive impairment | 9 |
| | Undiagnosed cognitive impairment | 9 |
| | No cognitive disorders | 5 |
| | Not tested | 5 |
| | | |
| **Delirium** | Diagnosis of delirium | 35 |
| | Undiagnosed delirium | 16 |
| | No evidence of delirium | 49 |

*Footnotes: Case definitions for each of the cognitive disorders are provided in Appendix 5.2*

Cognitive impairment was identified in nine participants, without evidence of further diagnosis being made. Of these, two individuals had diagnosed delirium, two had evidence of delirium not formally diagnosed, two had challenging behaviour or depression with involvement of the hospital-based psychiatric liaison team, two cases where no follow-up or investigation was conducted and one diagnosed with depression.

28% were prescribed cognitive enhancers and 17% anti-psychotic medications. Of these 18% were used in those who had co-morbid psychiatric history and 12% in those with behavioural and psychological symptoms of dementia (BPSD) or recognised 'behavioural disturbance' on admission.

### *5.4.5 Events documented during admission*

The median length of stay was 78.5 days (range: 14-231 days). Transfers of care were common, with 20% having one transfer, 47% having two transfers, 23% having three and 8% having more than three transfers during their admission and data missing for two individuals. Transfers were between parent wards, to rehabilitation settings, step-down care or boarding. 50% of the cohort received off-site rehabilitation/complex discharge planning before discharge to care home and 45% experienced boarding.

### *5.4.6 Multidisciplinary Team involvement*

Physiotherapists saw 92% of the participants and their input was incorporated into the final discharge plan in 60 cases. Occupational therapists assessed 53% of participants and their input was incorporated into the final discharge plan in 42 cases. The hospital Social Work team was involved in 93% of cases.

### *5.4.7 Advance Care Planning*

51% of the group had a Section 47 Adults with Incapacity (AwI) certificate and 10% had an advance statement. 45% had a recorded Power of Attorney or Guardianship order of whom 53% had an AwI certificate. 40% had a Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) order in their case notes.

### *5.4.8 Continence*

Only 25/89 (28%) were documented as fully continent at time of hospital discharge (excluding those with no admission continence data), compared with 62% recorded as fully continent on admission.

### *5.4.9 Cognitive enhancers & anti-psychotic medications*

4/28 (14%) had their cognitive enhancers stopped during admission and 4/72 (6%) were newly commenced on them. 2/17 (12%) had their anti-psychotics stopped during admission and 13/83 (16%) were newly commenced on them.

### *5.4.10 Discharge planning*

In 42% of cases concerns about the individual's ability to cope living at home were raised on admission, 76% of these being raised by family members. Documentation of discharge planning was first discussed on a median of six days into admission (range 0-249). 55% were in the acute hospital when the decision for a care home was made and 44% of them were discharged directly from the acute hospital.

The decision for care home admission was made on a median of 26 days after admission (range 0-249). The commonest main reason for the decision was family request (35%), followed by dementia (20%) and mobility limitations (9%). For five individuals, care home admission was at their own request.

## 5.5 DISCUSSION

### *5.5.1 Findings in context*

This cohort study of 100 patients provides the first characterisation of those admitted to a UK hospital and newly admitted to a care home: median age 83.6 years, mostly female with high levels of dependence, polypharmacy, incontinence and cognitive impairment. The overall picture is heterogeneous, with long hospital admissions, frequent transfers of care and varied levels of documented assessment.

This sample is representative of those admitted to care homes in the UK: prior participants in UK care home research are, on average age >80 years, majority female and with evidence of polypharmacy (Gordon *et al*., 2014). Most are widowed and lived alone, both identified as important predictors of need for institutional care in people with dementia (Luck *et al*., 2008, Banerjee *et al*., 2003). Levels of formal state-provided support were high (73%), reflecting the availability of free personal care for older adults in Scotland (Scottish Government, 2015a). Recurrent hospitalisations, experienced by over a third of this cohort, are known to be associated with downward trajectories of disability among older adults (Gill *et al*., 2015) and can be an important indicator of increasing care needs.

All admissions were unscheduled and most were under medical specialties, following common presentations in an older adult population (Inouye *et al*., 2007). Length of stay is prolonged

(mean 78 days) compared with the 2010 whole Scottish population average of 5.7 days (Office for National Statistics, 2010). Frequent transfers of care (31% moved ≥ three times and 45 experiencing boarding, meaning they were moved to another ward out with the speciality they had been admitted-to) have been associated with poorer outcomes for hospitalised older people (McMurdo and Witham, 2013). However, some transfers (also known as ward or hospital moves) were to allow access to rehabilitation in a non-acute hospital setting which is known to be associated with improved rates of independence (Green *et al*., 2005).

Cognitive disorders – dementia (Zekry *et al*., 2009) and delirium (Witlox *et al*., 2010) – are known to be associated with an increased risk of institutionalisation. The prevalence of cognitive disorders in the sample was very high, only five individuals had no evidence of cognitive impairment. Delirium was unrecognised in one-third of cases. Clinicians must ensure discharge processes support those with cognitive disorders, including those lacking capacity. The use of case note review methodology allowed inclusion of people lacking capacity without burdening them or carers with a direct approach for participation in a research study.

Incontinence has previously been identified as a predictor of institutionalisation (Nuotio *et al*., 2003, Grover *et al*., 2010). It is noteworthy that two-thirds were documented as fully continent on admission and less than a third were continent at discharge, and the reasons for this are being explored locally.

Functional status is an important predictor of care home admission following hospitalisation (Covinsky *et al*., 1997) and assessment should involve the MDT. Just over half of the cohort had documented assessment by Occupational Therapy in contrast with more than 90% being assessed by Physiotherapy and hospital Social Work. It is likely that functional needs were discussed in MDT meetings and detailed assessment (beyond observations of experienced nurses) not felt to be appropriate, but this was not recorded in the case record. The latest National Institute for Health and Care Excellence Guideline about transitions of older people between health and social care (National Institute for Health and Care Excellence, 2015a) recommends comprehensive assessment for older people with complex needs by an MDT, although it is flexible on who should be involved in the team (National Institute for Health and Care Excellence, 2015a). High-quality specialist assessment is advantageous for an individual's ongoing management within a care home setting (Challis *et al*., 2004), provided such information is shared (Oliver *et al*., 2014).

Concerns about the individual's ability to manage at home were frequently raised on admission to hospital and discharge planning was discussed early, in keeping with current policy approaches in favour of early discharge planning (Fox *et al*., 2013). The formal decision for care home admission was appropriately later in the admission for the majority.

Primary reasons for care home admission concur with known predictive factors of care home admission from the community (Luppa *et al*., 2012, Afram *et al*., 2014, Buhr *et al*., 2006).

### *5.5.2 Limitations*

The main limitation is that the information was extracted from ward-based case notes. Undocumented conversations could not be included and there is no way to determine the

frequency or scale of this issue. Information entered in the notes by Social Workers was included, but could not include the detailed social assessments which are entered by Social Workers on a separate electronic system. Increased use of electronic health records and integration of health and social care should help to improve this. Some important clinical information, such as cognitive function and mobility at discharge, is also not routinely re-assessed or recorded. It is not possible to comment on the documentation made by specific professional groups within the multidisciplinary team as these data were not recorded.

Another limitation relates to the sampling approach. A consecutive sample of discharges was sought, however coding inaccuracy, unavailable records and missing data required the screening of 273 case notes to obtain 100. Identifying coding inaccuracy is important to ensure the integrity of the study. All of the included sample were discharged to a care home, having previously resided in a non-institutional setting as this was confirmed by the researcher. However, this highlights the potential for the use of routine hospital data to misclassify residency status. Exclusion of cases based on missing data and unavailable records introduces the potential for selection bias. Records excluded due to missing data could represent those whose care was uneventful, those who were cared-for in a setting in which case-note documentation was infrequent or those whose care was sub-optimal. However, this potential bias has to be balanced against the aim which was to evaluate the assessment processes and decision. This is a pragmatic health services research study and for the findings to have validity, this evaluation cannot be made with confidence if records are incomplete, missing completely or destroyed. Paper-based records are susceptible to missing data and cannot be simultaneously used for detailed case-note research and clinical care. If the reasons for missing data and unavailable records were non-random, this would result in a biased sample. The results for this cohort are, however consistent with previous findings, and informative.

Data extraction was performed by a single researcher and thus creates the potential to introduce bias. However, the data extraction tool was developed and piloted with a wider group of clinicians and researchers. Furthermore, data extraction was not based on any pre-specified hypotheses so there is no reason to predict bias in one particular direction. Double data extraction could have been performed on a proportion of case notes to further reduce the potential bias.

Data were collected at a single centre, so the issues may not be more widely applicable. These data allow practitioners to review their own local service and processes for this common clinical scenario. The absence of primary research in this area is striking and further research is needed to define best practice in care home decision-making.

A case-control study was not performed, and so it is not possible to compare the experiences of this cohort with those who were not discharged to a care home. This sample also has a ‘survivor bias’ as only those who lived through their hospital admission to be discharged were included.

Finally, the voice of individual patients is not heard through the assessment of ward-based case notes and this is problematic in evaluating decision-making. Although recognising the complexity and individuality of each person being admitted to a care home, the lack of established formal standards of care and variations in national practice must raise concern.

### *5.5.3 Conclusions*

To ensure the right decision is made with each individual, the development of standards in the assessment of an older person in hospital being discharged to a care home is advocated. These would provide a framework to support the individual, the family and the hospital team in making this life-changing decision.

## 5.6 REFLECTIONS AND FURTHER DISCUSSION

New institutionalisation following acute hospital admission is common following UK inpatient hospital care and the lack of prior research about this is striking. The dialogue with professional stakeholders and practitioners locally and across the UK arising from the dissemination of these findings has been extremely interesting and merits further reflection. In addition, while case-note review methodology provided a useful exploratory method to begin this scoping project, it has inherent limitations. Many of these were discussed within the text of the original Discussion (Section 5.5 above). Here, I reflect further on how future studies might be improved by integrating what has been learned during data analysis.

### *5.6.1 Involvement in decision-making*

An additional finding not presented in the published paper (Harrison *et al*., 2017a) concerned the documented level of involvement of both the patients and their families in the decision about moving to a care home. Case-note review found evidence of only 37% of patients being involved in the decision, in stark contrast to the 92% of families and 97% of cases of MDT involvement. The threshold used to define 'evidence of involvement' was low, not requiring patient agreement, merely that there was evidence that the person had been consulted on this life-changing decision. This should be seen as a matter of concern and is out of keeping with the wider policy narratives about shared decision-making, highlighted by use of the phrase, "*No decision about me, without me*" (Coulter and Collins, 2011). Furthermore, suggestions that this simply reflects omissions in documentation seemed at odds with the high level found of documentation of family involvement.

When the findings were presented to clinical audiences, locally and at national events, there was a lack of surprise, with many sharing accounts of their observations around older people's lack of participation in decision-making and poor communication in hospital. While reassuring that the findings are considered to have external validity, this also suggests the need for awareness raising and improvement.

### *5.6.2 Determining capacity*

The Adults with Incapacity (Scotland) Act 2000, is the legislation which exists to support decision-making for adults who lack the capacity to make decisions for themselves (Scottish Parliament, 2000), and is often abbreviated to 'AwI legislation'. Incapacity is clearly defined in Scot's Law (**Table 5.4**). Importantly, the presumption is that an individual has capacity until proven otherwise and that capacity is decision-specific (Scottish Government, 2008).

**Table 5.4: Definition of Incapacity in Scots Law** (Scottish Government, 2008)

| |
|---|
| For the purposes of the Act, "incapable" means being incapable of:<br>- acting on decisions; or<br>- making decisions; or<br>- communicating decisions; or<br>- understanding decisions; or<br>- retaining the memory of decisions<br>in relation to any particular matter due to mental disorder or inability to communicate because of physical disability. |

In the context of medical treatment, the current documentation to be completed is a Certificate of Incapacity under Section 47 of the AwI act (Scottish Government, 2009). Data were collected in the study on the presence or absence of that Certificate during the hospital admission. It would have been preferable to have recorded the reason for the Certificate (for example, dementia, delirium, learning disability etc.) and the duration for which it had been active, to establish whether the individual lacked capacity to determine their medical treatment for a temporary period or throughout their admission. Even with more detailed recording, as capacity is decision-specific and these Certificates relate to the ability of the individual to make health and care decisions, they cannot be used as a proxy measure for the individual's ability to participate in other discussions and decisions. It cannot be assumed that these individuals lacked capacity to determine their future preferred place of care or, at the very least, to be involved in discussions about it.

The presence or absence of a Power of Attorney (PoA) or Guardianship Order was also recorded as a single metric. Having a PoA in place, however, does not necessarily indicate that an individual lacks capacity, instead it is a document completed when the individual retains capacity to nominate someone else to act on their behalf in the event of loss of capacity. It is registered with the Office of the Public Guardian for Scotland and is encouraged as part of current advance care planning policy (NHS Scotland and Scottish Government Health Delivery Directorate Improvement and Support Team, 2010). A PoA document in Scotland can provide general powers, continuing powers (termed financial powers) and welfare powers, or a combination of these three (Office of the Public Guardian (Scotland), 2017a). Although financial powers may be given when a person still retains capacity, but chooses to have the support of their attorney in their financial affairs, welfare guardianship typically requires activation in the event of incapacity (Office of the Public Guardian (Scotland), 2017a). This requires a statement of how incapacity is to be determined, to be specified at the time the PoA is issued (Office of the Public Guardian (Scotland), 2017a). The process of activating the PoA relies on fulfilling the criteria specified to determine incapacity (Office of the Public Guardian (Scotland), 2017b). As such, the presence or absence of a PoA is an unhelpful metric to collect and requires knowledge of these more individualised factors. A Guardianship Order, on the other hand, is only granted in cases where individuals have lost capacity to take decisions and permission is granted through the court system to allow someone else to act on their behalf (Scottish Government, 2013). Recording these separately and indicating more details about the PoA might have enabled analysis of those who were considered to lack capacity to make healthcare decisions at the time of their admission. In discussion, some practitioners stated that the explanation for the low level of patient involvement is because of the high prevalence of dementia and likelihood that

individuals lack capacity, meaning that involvement would not be appropriate or necessary. This explanation is not only at odds with my personal views, it is also not supported by one – 'Principle Three – Take account of the wishes of the person' – of the five key principles which should be applied by those who are authorised to make decisions on behalf of those who have impaired capacity (Scottish Government, 2008). This states that:

> "*In deciding if an action or decision is to be made, and what that should be, account must be taken of the present and past wishes and feelings of the person, as far as this may be ascertained. Some adults will be able to express their wishes and feelings clearly, even although they would not be capable of taking the action or decision which you are considering.*" (Scottish Government, 2008)

This clearly acknowledges that decisions should not be taken without the involvement of the individual and differentiates the ability to decide on, for example, future place of care, *versus* preferences about this, countering the challenge presented by some clinicians. Interestingly, *post-hoc* quantitative analysis to explore the hypothesis showed no evidence of an association between dementia diagnosis and involvement ($\chi^2$ 1.78 p 0.18; N with dementia = 59, 42% involved; N without dementia = 41, 29% involved) or the use of Section 47 Incapacity Certificate and involvement ($\chi^2$ 3.15 p 0.07. N with Section 47 Certificate = 51, 29% involved; N without certificate = 47, 47% involved). Although the limitations of these data are evident, they provide an interesting challenge to those who excuse the lack of evidence of involvement on grounds of dementia or incapacity.

Criticism of these findings is not intended to underestimate the complexity of discharge decision-making in the context of cognitive impairment and impaired capacity and with the limited insight which is possible from case-note review alone. Ethnographic research conducted in the North East of England examined discharge decision-making in hospital inpatients with dementia (Poole *et al*., 2014). This not only identified the complexity of these decisions, but also the time required to evaluate capacity and best interests and the need for better documentation (Poole *et al*., 2014). Although in the context of the Mental Capacity Act (applicable in England & Wales), this research identified tensions in balancing the concepts of 'autonomy' and 'risk' and how professionals may not fully apply the standards of the legislation in their attempt to achieve their perceived 'best' outcome for the individual patient (Emmett *et al*., 2013). Similarly, review of Guardianship applications in Scotland found that just under half (47.5%) lacked a statutory definition of capacity and applications for older adults were more poorly completed than those for younger individuals (Russ *et al*., 2016). These examples of applied research provide valuable insights into the everyday application of legal process in UK hospitals and, even accounting for the differences in law, how the principles enshrined in legislation may not be upheld in practice.

### *5.6.3 Documentation as evidence*

A further challenge raised in the interpretation of the findings is the extent to which case-note review can be used to judge the experiences of the individuals described. Although acknowledging that not every interaction or conversation in hospital will be recorded in case notes, it was anticipated that significant discussions, such as those around change of residence, would have been documented. Previous research conducted in hospital (Hyde *et al*., 2005) and long-term care settings (Broderick and Coffey, 2013) identified deficiencies in nursing

documentation when demonstrating person-centred care and involvement of the individual in their care planning. It is noteworthy that there was a much higher level of documented family involvement than involvement of the individual – perhaps suggesting a greater imperative to record these interactions rather than those with the patients themselves.

Case-note review using a structured holistic approach is considered a feasible way to assess quality of care, although differences exist between healthcare professionals in their approaches to case-note review (Hutchinson *et al.*, 2010). The project benefited from having a single assessor evaluate all the case notes, supported by more senior colleagues, thus reducing the potential for variation in evaluation.

There are now established standards with respect to the structure, format and content of documentation in case notes, which identify the key aspects which should be included in medical record-keeping (Health & Social Care Information Centre and Academy of Medical Royal Colleges, 2013). Increasingly, there has been a drive to improve quality in the care provided, particularly to older people, in Scottish hospitals with a programme of inspections based on care standards (Healthcare Improvement Scotland, 2015). Two of these standards pertain directly to the involvement of the older person in their own care, treatment and decision-making (Healthcare Improvement Scotland, 2015). In addition, many of the other standards are measured by observations of practice and review of documentation as an evidence source (Healthcare Improvement Scotland, 2012). Case-note review is also a source of evidence used when considering cases where the quality of care is questioned and subject to review. The office of the Scottish Public Health Ombudsman reviews cases where concerns about care have been raised and a 2013 case was critical about the lack of involvement of an individual with dementia (Scottish Public Service Ombudsman, 2013). Although that specific case pre-dates the study, it is nonetheless a reminder of the formal ways in which care is evidenced, or not, and the importance of good documentation to evidence care.

### *5.6.4 A human-rights based approach*

Having identified a lack of patient involvement and with family request and dementia cited as the most common reasons for care home admission, a broader question is raised regarding respecting and supporting the rights of the individual. The concept of a 'human rights-based approach to care' has become increasingly prevalent, is persuasive and worthy of further discussion. There is a recognition that while everyone has human rights, including a right to health, health inequalities are prevalent in Scotland and not all Scottish citizens are able to realise their rights (NHS Health Scotland, 2016). To start to address this, it is necessary to engage more broadly with the social determinants of health and ensure that the delivery of health and social care services is driven by a human-rights based approach to the benefit of wider society (NHS Health Scotland, 2016). The PANEL principles (**Table 5.5**) have been proposed to help care providers, policy makers and those in Government deliver their activities with a human-rights based approach.

**Table 5.5: The PANEL approach** (ALLIANCE: Health and Social Care Alliance Scotland, 2013)

| |
|---|
| **P** – participate in decisions which affect their human rights<br>**A** – accountability of those responsible for the respect, protection and fulfilment of human rights<br>**N** – non-discrimination and equality<br>**E** – empowerment to know their rights and how to claim them<br>**L** – legality in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements |

One such example is that of Alzheimer Scotland which seeks to:

> *" campaign for all legislation and policy in Scotland to reflect a rights-based approach for people living with dementia, their families and their carers"* (Alzheimer Scotland, 2017).

This provides important recognition that issues for people with dementia are not confined to health and social care and that broader engagement with policy and the law is important. With the Cross-Party Group in the Scottish Parliament on Alzheimer's, Alzheimer Scotland worked with patients, carers and professionals to develop the *Charter of Rights for People with Dementia and their Carers in Scotland*. This charter is based on the PANEL approach (**Table 5.5**). In addition to reiterating the need for anyone acting on behalf of a person who lacks capacity to uphold the principles of the AwI Act, the Charter also makes this specific recommendation:

> "*People with dementia and their carers have the right to full participation in care needs assessment, planning, deciding and arranging care, support and treatment, including advanced decision making*."(Cross-Party Group in the Scottish Parliament on Alzheimer's, 2009)

This is a challenge to those who deny the participation of individuals with dementia from discussions about their care needs or preferences. While not every patient with dementia may be able or willing to participate in the decision-making process, there is little justification for attitudes which seek to exclude them or not to elucidate their wishes. It is important that healthcare professionals are aware that the culture of the patient—professional relationship is changing, with increasing recognition of the role of the individual, their needs and their rights. This offers challenges to how healthcare is organised and how we evidence our decisions, involvement of the patient and their carers and their views and values. Moves away from hierarchical relationships in medicine are welcome, but these rely on effective communication and individualising approaches based on specific needs. It is imperative that these changes, such as the promotion of person-centred care in dementia, are supported by tangible changes in policy, culture and attitudes to ensure they are more than just platitudes (Brooker, 2004).

### *5.6.5 Role of Social Work staff*

A significant limitation of the study was the lack of the Social Work records in the data collection. These are recorded on a separate electronic system and documentation in the ward-based case notes by the Social Work team was generally limited to recording attendance on the ward and that an assessment had been conducted. This had not been anticipated and means the ward-based records lack any information about the assessments performed and the information obtained by the Social Work staff, which may prove critical in understanding the individual and their values and preferences. An increasing challenge in NHS hospitals is the lack of availability

of Social Work staff, meaning that they are typically not attached to a specific unit, distributing their case load on the basis of the needs of inpatients across the hospital. While this may facilitate a more rapid assessment process, it may mean that Social Work staff are not generally an integrated part of the ward-based MDT and there may be a lack of understanding of their role and capabilities.

Feedback was, however, received from the Lead for Social Work within the hospital that information about the involvement of the person would have been identified in the Social Work notes, as the perception is that social care evaluations are broader in scope and information than those conducted by healthcare professionals. It is therefore important to consider why this information is not more easily shared among the MDT. Kitwood first argued that the medical model of dementia was failing those who lived with the condition and emphasised the need to value the person themselves (Kitwood, 2004). The ward-based notes are dominated by documentation from medical and nursing staff and it is possible these may focus on the medical issues rather than the person. This 'disconnect' raises the crucial question of whether person-centred assessment in hospital is solely the remit of one profession and, if so, which one? In the context of the integration of health and social care, availability of shared notes seems essential to reduce repetition of data collection and facilitate a comprehensive assessment of the individual to which all team members can contribute. It may also allow all professionals involved in the person's care to be more focused on the person, rather than on their 'medical issues'.

### *5.6.6 Exploring the role of undiagnosed cognitive impairment*

The original research question developed by the study team was to explore the role of undiagnosed cognitive impairment in the process of new institutionalisation following hospital admission. The prevalence of cognitive impairment within the sample as a whole meant that any formal statistical comparisons between groups would have been of only limited value because of the small groups identified within the cohort. The data analysis presented is therefore descriptive, rather than the quantitative analyses originally planned. In addition, it did not make clinical sense to group those with undiagnosed delirium, as determined from case-note review, in the same group as those with cognitive impairment without any diagnosis, as data were lacking on the resolution of delirium, duration of cognitive impairment or the extent of functional impairments in those with cognitive impairment, to help suggest whether dementia was possible or not. Further exploration of this hypothesis would benefit from data evaluating a larger sample of the entire population of older adults, including those with diagnosed and undiagnosed cognitive impairments and their outcomes following hospital admission.

Specific effort had been made within the data collection form to record evidence of undiagnosed delirium, including evidence of cause, duration, treatment and any record of the diagnosis. However, the case records were limited in the documentation of these key variables, particularly when delirium resolves. In clinical practice efforts are being made to improve the recognition and management of delirium through the provision of resources, education and quality improvement (Healthcare Improvement Scotland, 2016). For future research, it would have been preferable to establish a more formal diagnosis of delirium, using a validated method for case-note review (Kuhn *et al*., 2014).

### *5.6.7 Numbers versus narrative*

While the topic of the work is novel, caution must be exercised to avoid over-interpretation of the data. This was apparent when discussing the findings within the group (which includes individuals with both quantitative and qualitative training, as well as medical and nursing expertise) and engaging with the limitations of translating the dynamic and varied processes of care in the hospital setting into a series of proportions and percentages. This can risk loss of the underlying individual stories within the data and also risks trying to over-simplify something complex. A single hospital admission may well be one episode in a much longer journey for the individual in health and social care services. Prior admissions were not considered in the analysis, but it is evident that multiple previous admissions are an important consideration for individuals and their families in making a decision for the need for 24-hour care. A second paper reporting the qualitative analysis of ten of the hundred cases has been published which sought to explore individual experiences in greater depth (Rhynas *et al*., 2018). A summary of findings is presented in Chapter 6, Section 6.5.2. Quantifying concepts such as involvement, agreement and participation is challenging and binary evaluation is a very stark way to describe the complexity of the interactions recorded in case notes. Even the experiences of the individual during their hospital admission, running over many days and weeks, was much harder to summarise than information about their initial admission. When conducting the analysis it was apparent how much the data collection form was weighted to baseline characteristics and discharge processes, with a relative lack of data about the admission itself. Future case-note review projects should carefully consider which data can and should be extracted.

## 5.7 CONCLUSIONS

This Chapter characterised a cohort of 100 individuals experiencing new institutionalisation following acute hospital admission, identifying them as typically female older adults with high levels of dependency, incontinence, polypharmacy and cognitive impairment. The overall impression is heterogeneous with long hospital admissions, frequent transfers of care and varied levels of documented assessment and involvement. Chapter Six will describe the development of the follow-up study and present illustrative analysis of a single dataset.

# CHAPTER SIX

# One chance to get it right: exploring perspectives and experiences in care home discharge decision-making

## 6.1 INTRODUCTION

The retrospective cohort study described in Chapter Five offered some insights into the variation among the individuals who are discharged to a care home from hospital and their in-hospital experiences. However, a key limitation of this methodology was the lack of patient voice which is available by reviewing case notes. There was no way to ascertain how the decision had been reached and findings, such as the documented lack of patient involvement, could not be fully explored. A qualitative case-study design was planned to explore these questions. This Chapter will discuss the research design and constraints imposed as a consequence of the process to obtain ethical approval. The Chapter will then describe recruitment and present the analysis of one dataset as an exemplar.

## 6.2 MOTIVATION

Acquiring experience in conducting qualitative research was a key objective during this Clinical Research Fellowship. The aim would be to continue to use mixed methods approaches in future research. Therefore it was essential to have gained practical experience to understand what is feasible and realistic.

The original intention was to conduct an interview study for hospital staff about discharge decision-making in adults with cognitive impairment. However, an opportunity arose after the Gibson Trust study (Chapter Five) to collaborate in a follow-up study, the 'One chance to get it right: exploring perspectives and experiences in care home discharge decision-making' study (henceforth abbreviated to the 'One Chance Study'). Involvement in the One Chance Study offered the opportunity to obtain experience in conducting qualitative research, including recruitment and interviewing. Data analysis and interpretation would be conducted as part of a supportive team with expertise in qualitative methods, allowing training and skills development. As the study has been conducted as part of a team and full data analysis is still ongoing, the complete analysis will not be presented here. Illustrative analysis of a single dataset will be presented and the focus will be on my role in the project.

## 6.3 EXISTING RESEARCH

Chapter One, Section 1.4 included a summary of research findings about discharge planning in the acute hospital. To focus the project described here, a focused but non-systematic search of the literature was made using PubMed and CINAHL to identify key qualitative research about care home admission from the acute hospital. Five key studies were identified, three which included older people and two which focused only on hospital staff.

The first of these five studies was conducted in two phases, interviewing older people and their family members after discharge to a care home and both care home and hospital staff about satisfaction around discharge procedures (Reed and Morgan, 1999). The older people perceived a lack of opportunity to discuss the significance of their change of residence and that they had a lack of control over their care. Families described being rushed to choose a home and pressure for their relative to be discharged (Reed and Morgan, 1999). Finally, staff described a lack of clarity about whose role it was to initiate discussions around care home decisions (Reed and Morgan, 1999).

The second was a mixed methods UK study which compared 32 individuals awaiting care home placement with 20 individuals awaiting discharge to receive care at home, with respect to their demographics, psychological wellbeing and response to care after discharge (Espejo *et al*., 1999). Those awaiting care home placements were more likely to be widowed or single; have lower cognitive performance and be more dependent, but also reported significantly less emotional support from friends or relatives (Espejo *et al*., 1999). The authors described different levels of acceptance among the cohort with respect to how resolved or unresolved they were to the decision and this was related to whether the decision had been initiated by the individual or not (Espejo *et al*., 1999). It is important to note the age of these studies, set against the significant changes in the organisation of inpatient care seen since then.

The third study interviewed cognitively intact older people who had decided to move into nursing care homes from hospital and from the community (Stevens *et al*., 2015). They found that those who had been supported by professionals and involved in the decision-making process were successfully "settling-in" (Stevens *et al*., 2015). Hospital admission was described as a key "turning point" at which future residency could be influenced, depending on the assessment and support provided (Stevens *et al*., 2015).

There is limited evidence on what affects discharge decision-making. Risk perception is an important example because it varies between individuals and is potentially modifiable. The two studies which included professionals only, interviewed occupational therapists and physiotherapists. The first used a structured case vignette to focus questioning (Atwal *et al*., 2012). This study found that negative language was often used by therapists to describe patients who wanted to take risks and that issues around capacity and safety influenced professional recommendations (Atwal *et al*., 2012). The second study focused on making recommendations for discharge placement in acute care (Jette *et al*., 2003). Those participants describe how patient-specific information (around functioning, disability, wants and needs and ability to participate in care) was considered alongside the professionals' experience, regulations within the healthcare system and the opinions of other team members in order to reach their recommendation (Jette *et al*., 2003).

Broadening the scope to include research which has been conducted involving community-dwelling older adults found a large study of professional perspectives and involved focus groups and semi-structured interviews with a total of 99 health and care professionals (Taylor and Donnelly, 2006). The authors noted that decisions about long-term care are often prompted by a crisis and that important external factors, such as funding, pressures on primary care and availability of home care, affect the decisions of individuals (Taylor and Donnelly, 2006). The scope of this study included admissions from hospital and from the community, but hospital

admission was increasingly recognised as the crisis triggering the decision (Taylor and Donnelly, 2006). Loss of confidence, particularly among those living alone, was identified as a significant trigger to care home admission, a domain often poorly captured in assessments focusing on physical health and dependency (Taylor and Donnelly, 2006). For those with family, their ability and willingness to cope with care needs were critical in determining who would require placement (Taylor and Donnelly, 2006).

No studies were identified in the acute hospital setting which explored this topic in people with dementia. Care home decision-making has been identified as one of the most problematic areas for the family carers of people with dementia who lack capacity (Livingston *et al*., 2010). Lord *et al.* explored this difficulty, by conducting interviews in England with people with dementia and/or their family carers in the community at the time of making the decision to move into a care home (Lord *et al*., 2016). Key issues were around the involvement of the person with dementia, safety, deterioration in physical health, uncertainties about disease progression and difficulties navigating the care system (Lord *et al*., 2016). These authors subsequently developed a decision aid to try to help support carers in decision-making, but they recognised that the acute hospital environment presented a different context in which its usefulness would need to be tested (Lord *et al*., 2017).

These identified papers provided insights into existing perceptions of the decision-making process and layers of involvement, but lacked detail around the process of decision-making in hospital. Several of the papers found date back nearly 20 years, which can limit their relevance to the acute hospital context of practice today. Understanding how professionals are working in the current health and social care system with patients and families to make these decisions, offers scope to identify good practice and areas for improvement.

## 6.4 AIM

The aim was to explore how decisions are made to discharge patients directly from hospital to care homes from the perspective of the key stakeholders in the decision-making process, exploring the factors which influence such decisions and how they were communicated.

## 6.5 METHODS

This Chapter has been reported incorporating the COnsolidated criteria for REporting Qualitative research (COREQ) checklist (Tong *et al*., 2007) components with additional narrative and discussion.

### *6.5.1 Study design*

Two methodologies were considered for the One Chance Study: ethnography and case-study methodology. Ethnography originated in anthropology, where it: "*… provides a description and interpretation of the culture and social structure of a social group…involving an immersion in the particular culture"* (Robson and McCartan, 2016b). Ethnographic studies require a dedication of time, regular observations, interviews and discussions with members of the group, termed

informants (Bryman, 2016a). A key consideration with an ethnographic approach to this question is that of reflexivity. Reflexivity is: "*… the relationship a researcher shares with the world he or she is investigating"* (Reeves *et al*., 2008). It has to be presented transparently, so the impact of the researcher's role can be gauged in terms of impact on the conduct and findings (Reeves *et al*., 2008).

Discussion with members of health and care staff questioned the role of a junior doctor in evaluating the organisation, decisions and performance of the ward-based multidisciplinary team multidisciplinary team (MDT). This need not have been an insurmountable barrier, but is important to acknowledge explicitly. Practical arguments related to the availability of researcher time (as part of this wider mixed methods thesis) and funding from a small grants scheme meant that an ethnographic approach was not considered a suitable or appropriate next step to research this topic.

Case-study research is considered a valuable methodology to *"investigate practical and policy questions in health care*" (Keen and Packwood, 1995). **Table 6.1** provides a detailed definition of case-study research.

**Table 6.1: Definition of case-study research** (From Yin, 2009)

| |
|---|
| (1) A case study is an empirical inquiry that:<br>- investigates a contemporary phenomenon in depth and within its real-life context, especially when<br>- the boundaries between phenomenon and context are not clearly evident.<br><br>(2) The case-study inquiry:<br>- copes with the technically distinctive situation in which there will be many more variables of interest than data points, and as one result<br>- relies on multiple sources of evidence, with data needing to converge in a triangulating fashion, and as another result<br>- benefits from the prior development of theoretical propositions to guide data collection and analysis. |

The approach taken here is to have a single case with embedded units (Baxter and Jack, 2008). The single case 'discharge to care home from the acute hospital' is constructed using data collected from individual datasets which have been gathered about specific individual patients and their circumstances.

Within case-study methodology, options existed around methods for data collection. Principally, this decision concerned interviewing individuals compared with organising focus groups.

Semi-structured interviews are described as those where:

> *"… the researcher sets the agenda in terms of the topics covered, but the interviewee's responses determine the kinds of information produced about those topics and the relative importance of each of them"* (Green and Thorogood, 2011a)

Interviewing requires skills, including establishing rapport and listening carefully to answers, both important components of clinical history-taking (Green and Thorogood, 2011a). Arguably therefore it is well-suited to practitioners with experience of interacting with patients. The

interviews can focus on a single individual and those providing support in the decision-making process.

Interviewing was considered preferable to organising focus groups. A focus group interview is:

> "*… a group interview on a specific topic... it is an open-ended group discussion which the researcher guides, typically extending over at least an hour*" (Robson and McCartan, 2016c)

Although considered a more efficient technique for collecting data, focus groups require skill in facilitating and ensuring attendees are able to participate (Robson and McCartan, 2016c). The value of gathering collective opinions in a discursive forum was limited, given this study's focus on the experiences of individuals. It was also recognised that the practicalities of organising focus groups of health and care staff were considerable.

Therefore, it was decided that case study methodology incorporating semi-structured interviewing, supplemented by case-note review, would be an appropriate choice to focus on specific individual patients and their families, to describe 'discharge to care home from the acute hospital'. The single case would comprise multiple datasets, each based around individual patients. A dataset for the purpose of the study was defined as:

- Patient participant interview
- Significant person participant interview (i.e. relative, carer, friend, if appropriate)
- Up to three MDT participant interviews (as determined by involvement/role)
- Ward-based case-note review

### *6.5.2 Methodological approach*

Data analysis was planned to include three stages, informed by the research team and recognised analytical approaches (Robson and McCartan, 2016a). Firstly, all datasets were inductively coded individually to identify themes pertinent to each. The same coding list was applied across all datasets, but additional codes were added as new themes were identified. The datasets were then compared, highlighting important commonalities and differences. Thereafter the analytical framework developed following our earlier work from the Gibson Trust Study will be used to compare and contrast the emerging findings of this study with prior work. Analysis was planned to take place within each dataset (within-case analysis), between the datasets (cross-case analysis) and across all the datasets using an analytical frame (cross-case analysis) to fully explore the data and create the overall single case (Baxter and Jack, 2008). Cross-case analysis was ongoing at the time of thesis submission.

A single dataset is presented here, illustrative of the wider approach. As such, the analysis provided is limited to the first stage (inductive thematic coding within the dataset).

#### 6.5.2.1 Analytical framework

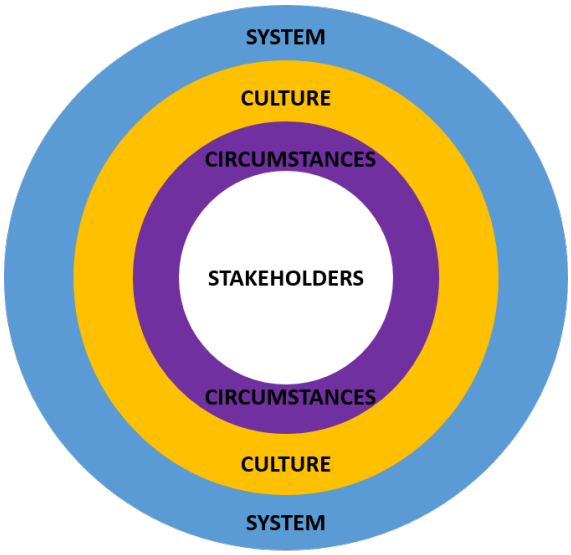
From the 100 cases included in the cohort study (described in Chapter Five), ten were purposively selected for in-depth qualitative analysis. Selection of these cases and analysis was led by Dr S Rhynas and Ms A Garcia Garrido. I was involved in the analysis and preparation of the findings for publication (Rhynas *et al*., 2018). The key findings from this analysis are described in **Table 6.2.**

**Table 6.2: Key findings from case-study narrative analysis**

| |
|---|
| 1. Care home discharge decision-making is complex, time consuming and decisions are not taken lightly |
| 2. The stakeholders (older person, hospital staff and any family members) have a range of expertise, experience and perspectives on the process |
| 3. Looking at the perspectives and involvement of the older person emphasised the need to incorporate their wishes regarding care home admission; to recognise complex care needs and to respond to unforeseen circumstances |
| 4. Considering the role, perspectives and involvement of family members identified issues around risk and coping; provided examples of the hospital admission as 'the final straw' and described their experiences making the decision, as recorded by hospital staff |
| 5. Evaluating the role, perspectives and involvement of healthcare professionals identified: their documented contributions to decision-making; the strength of professional continuity and; revealed interesting narratives around risk and whether 'failed discharge' is a term which needs to be re-conceptualised around the needs of older people on the verge of admission to long term care |

Reflecting on these findings and the existing literature described in Section 6.3, I developed an initial broad analytical framework to apply to the findings of the One Chance Study (**Figure 6.1**). This framework has not been used previously, but will be applied to the analysis of all data collected from the six datasets.

**Figure 6.1: Analytical framework developed from the Gibson Trust narrative analysis**




The framework is presented in four levels, with the **stakeholders** at the centre. Stakeholders may include the individual patient, their family, carers or appointed representatives and members of the MDT. For each stakeholder group it is necessary to consider their role and involvement in decision-making, perspectives on the decision and their expertise, if applicable. The next level in the decision-making process is the **circumstances** in which the individual finds themselves in. Key concepts to be considered here are the reasons for hospital admission, the care needs of the individual and complicating unforeseen circumstances, such as death of a

spouse or flooding affecting prior residence. Moving outwards to the **culture** surrounding decision-making. This particularly related to attitudes towards risk and coping and could be seen both as organisational culture and culture within and between professional groups. 'Failed discharge' – anecdotally described as where an individual is readmitted rapidly after discharge due to a breakdown of their social support – sits between culture and the system as a concept relevant in care home decision-making . Culture is also inextricably linked to the final level of the health and care **system** in which decisions are being taken. This requires considerations of external and internal pressures, time and the wider organisation. These levels served as theoretical propositions developed, prior to data collection and analysis, to test the data against previously identified features (Baxter and Jack, 2008, Yin, 2009).

### *6.5.3 Research team*

There were three researchers conducting interviews to collect data for this study, myself (JKB – a junior doctor and researcher), Ms Azucena Garcia Garrido (AGG – a community nurse and researcher) and Mrs G Logan (GL – a staff nurse and researcher). The project team, comprising senior nurse researchers, oversaw the day-to-day work, with input from senior academics in the project collaborator group. External input was received from the study advisory board which also included a lay perspective, social work involvement and senior clinical nurses.

Face-to-face training was completed in both informed consent and good clinical practice. Interview practice sessions were arranged within the project team and the initial interviews I conducted were replayed among the project team to develop experience and improve consistency of approach.

None of the interviewers were involved in the clinical care of the patients recruited and did not know any of the significant persons. Some members of the MDT were known to the interviewers, although not as direct supervisors or employers.

### *6.5.4 Sampling strategy*

**Eligibility**: In order to be eligible for recruitment, potential participants needed to be:

- Adults aged ≥ 18 years
- Able to communicate in English
- Inpatients in Medicine of the Elderly or Stroke of the Royal Infirmary of Edinburgh or Western General Hospital
- Able to consent to participate
- Not assessed as lacking capacity to make complex health and welfare decisions
- Living in non-institutional care before admission
- For whom a decision has been made during this hospital admission to move into a care home on a permanent basis.

A recruitment checklist was pre-specified and included a list of characteristics of interest including: age, sex, living alone, family support, package of care, previous hospital admissions and diagnoses including dementia, stroke and falls. The date of decision for care home and reasons for care home were also recorded.

**Sampling**: A purposive sample of participants was sought, to represent a range of characteristics of interest and ensure variation in the sample (Bryman, 2016b). In practice, a single participant was recruited at a time and their key characteristics were shared within the study team. Specific effort was made to ensure at least one dataset involved an individual who had experienced a stroke and an individual with a diagnosis of dementia.

**Approach**: The researchers attended the wards regularly and spoke with medical, nursing and therapy staff to enquire about any patients for whom the decision had been made that they would be moving into a new care home placement at the time of their hospital discharge. A record was kept of the total numbers whom the staff felt lacked capacity to consent. For individuals the staff thought may have capacity, staff were asked to speak to the patient and provide assent for the researcher to approach and discuss the study.

**Assessment and participation**: Where assent was provided, the researcher approached the patient, initiated discussion and introduced the study if they thought it was appropriate. Capacity is defined as: "*the ability to act, make decisions, communicate decisions, understand decisions and retain the memory of decisions*", based on the Adults with Incapacity (Scotland) Act (Scottish Parliament, 2000). Capacity to consent to participate was assessed by the researcher, over the course of more than one visit, with information tailored to the individual patient circumstance and cognitive function. If the patient was assessed as having capacity they were invited to participate in the study and recruited if agreeable. If the patient was assessed as lacking capacity to consent, they were thanked for their time. Recruited participants were free to decline to participate at any time, without providing any explanation to the researcher.

**Sample size**: Section 6.5.1 describes the components of a dataset for the study. The funding received for the study supported the collection of a maximum of eight datasets, based on eight patients recruited, with up to an additional four interviews per patient to include significant persons and members of the MDT (Total estimated maximum n=40). The final sample size included in the study (27 interviews with n=30 participants; six datasets) was determined by availability of eligible participants, agreement of significant persons and members of the MDT to participate and funded researcher time for the others involved in the project.

### *6.5.5 Recruitment*

Data were collected in the Medicine of the Elderly and Stroke wards of two large teaching hospitals: the Royal Infirmary of Edinburgh (RIE) and the Western General Hospital (WGH), Edinburgh between June and November 2017. Interviewers were based at a single site for participant recruitment – JKB at RIE and AGG and GL at WGH. Prior to study commencement, contact was made with the Consultants and Charge Nurses of all the wards included in the study and the research team attended meetings to describe the study, agree on an acceptable recruitment approach and support the release of staff to participate.

**Patient participants**: Participants were offered the chance to involve family members in the recruitment process and/or staff to assist them. Patient information was provided in standard and large-print versions and was read aloud to those with significant visual impairment. All patients were given time to consider their participation, before seeking written consent. The

interviews were scheduled on a separate occasion at the choice of the patient. Before starting the interview, capacity and willingness to participate were reassessed.

**Case-note review**: After the patient interview was complete, review of the ward-based case notes was conducted to identify members of the MDT who seemed to have been involved in the process.

**MDT participants**: Members of the MDT were approached, usually in person but telephone was required to contact non-hospital based practitioners. All MDT members were given information about the study, time to consider and the opportunity to decline to participate.

**Significant person participants**: Significant persons were approached, either in person or by telephone. An arrangement was made to meet, provide information about the study and an opportunity to consider. Their capacity to consent was established. Significant person interviews were conducted at the RIE or the person's home, depending on their availability.

Written informed consent was obtained from all participants. Copies of consent forms were supplied and an additional copy stored in the ward-based case records. The ward Consultant, Charge Nurse and GP were informed in writing of the patient's participation in the study. All participants were included, irrespective of participation from their significant person or members of the MDT.

### *6.5.6 Interviews*

A semi-structured interview guide was developed through discussion among the project team. Questions were divided into those concerning pre-admission circumstances, the hospital admission and the care home decision. Brief introductory text was drafted to improve consistency between interviewers. Questions were tested within the study team and refined to improve wording, particularly ensuring they represented spoken rather than written questions. A separate interview guide was developed for each of patient participants, significant persons and members of the MDT, although their overall structure was similar.

After the first dataset was completed, I offered suggestions for adjustment to the order and salience of questions; added specific questions I had found fruitful in the interviews (such as whether the documentation reflected the activity undertaken) and drafted a closing question designed to invite contributions from the interviewee which had not already been covered. We discussed these suggestions and agreed wording to update the interview guides. This helped to ensure subsequent interviews built on the earlier ones and influenced data collection.

All interviews were audio recorded and the recordings submitted electronically for transcription by an approved NHS transcription service. One patient transcript was rejected by the service due to difficulties understanding the patient's accent and speech pattern. I transcribed this independently. Interview length was determined by the interviewee's responses, with most MDT interviews lasting up to 30 minutes and other interviews ranging from 20 to 80 minutes.

Transcripts were checked for accuracy by the project principal investigator (GL). Accurate copies were sent by email to the study team members for analysis.

### *6.5.7 Case-note review*

Review of the ward-based case notes was planned for all participants. A data extraction form was created and modified to identify core information. Collecting these data was to enable evaluation of how the experiences of the individual, their family and the members of the MDT were documented. This was to help establish whether reviewing case notes can be considered a reliable method to identify the experiences of these individuals.

### *6.5.8 Analysis*

A summary vignette was written to describe the clinical background and the participants in the dataset. These were written by the individual who had conducted the interviews for each dataset.

To start the formal analysis process, transcripts were read repeatedly (Thomas, 2006). The first readings were made without any additional notes being taken. Thereafter, I highlighted the paper transcripts, dividing the content into the key sections of the interview: home circumstances; hospital admission; the care home decision; perceptions of care homes; the documentation and the wider health and care culture influencing the process. This generally reflected the pragmatic order of the interview, but often respondents reiterated important aspects or returned to these later. I wrote a narrative summary of key issues emerging from each interview within the dataset as an analytic tool to record each interview's key points.

A list of codes or phrases was generated which represented key concepts or themes encountered in the data. Each of the project team generated independent lists of codes. I then presented my code list to the group. We discussed the meaning of these codes and refined the list to find terms with shared meaning. Once we had an agreed list, the transcripts were imported into NVIVO Version 11. The agreed code list was applied to each dataset. I coded the dataset presented here and recorded modifications to coding which emerged on more in-depth analysis at the time. No framework was used to guide this initial inductive thematic analysis. The later stages of analysis described in Section 6.5.2 will use the Analytical Framework displayed in Figure 6.1, developed following the previous research (Rhynas *et al*., 2018).

After coding had been completed on two of the six datasets, the team reviewed the coding list and analytical approach. Comparisons were made between the datasets, highlighting key similarities and differences. The research questions were revisited and data examined with respect to how they contribute to answering the original study aim. At each stage of the analysis, effort was made to return to these questions and, although they cannot be fully answered using a single dataset, key findings will be presented here.

### *6.5.9 Ethical approval and permissions*

The original protocol planned that the study would include both adults who have and who lack capacity to consent to participate. The project was submitted for review by the Academic and Clinical Central Office for Research and Development (ACCORD) in September 2016. The project was reviewed in January 2017 by the Scotland A Research Ethics Committee (REC), who

provided an unfavourable opinion (Appendix 6.1). The Committee determined that the study could be carried out without the inclusion of Adults with Incapacity (AwI) on the grounds that:

> "*The Committee did not think that the purpose of the research is to obtain knowledge on the causes, diagnosis, treatment or care of adult's with incapacity or the effects of treatment or care given during his/her incapacity which relates to that incapacity.*"

The other criteria were all deemed to have been satisfied. They advised a resubmission of the application with either: all adults who have capacity; all adults who lack capacity or; divide the sample in half and compare the experiences of those with and without capacity.

This presented a challenge to the progress of the study and reflection about the purpose and value of the research, considering capacity and research participation.

#### 6.5.9.1 Capacity, incapacity and research participation

The meaning of 'incapacity' from the perspective of the REC refers to being unable to consent to participate in the study. This means being unable to understand, retain and communicate the information around participation in an interview which would be audio-recorded and permission to contact family members, ward staff and to review case notes. This is potentially different from the wider issue of capacity around medical care and, crucially for this topic, decision-making around future place of care and residency.

Intuitively, those who lack capacity are those whom this research aims to help, their likelihood of being vulnerable to paternalistic decision-making and exclusion from the process is much greater. However, the reality of their likely degree of cognitive impairment is important to acknowledge and the ability to describe involvement in decision-making and staff support in hospital may be more limited. One of the aims of this work was to identify good practice, areas for improvement and, crucially, to hear the patient voice. As discussed in Chapter Five, Section 5.6.2, there was a lack of data on capacity among the target population as all the measures collected were proxies.

Ideally, it would be preferable to define the study population based on their capacity to make decisions about residency. However, defining this sample would be practically difficult and it would not necessarily divide down lines of capacity to participate in research or not, as there are likely to be individuals who cannot make the decision about place of care, but could consent to participate in exploratory qualitative research. The alternative approach suggested, to make a comparative analysis between those with and without capacity to consent, fundamentally alters the question. Here the research question becomes what are the similarities and differences between those who have capacity to consent to be interviewed *versus* those who lack capacity to consent to be interviewed. This does not necessarily represent two clinically meaningful groups of patients, nor help to identify what best practice in this area should be.

#### 6.5.9.2 Revised submission to ethics

After careful consideration, the study protocol was revised to include only adults with capacity to consent to participate. This was re-submitted and reviewed at the West of Scotland 4 REC in

March 2017 [REC 17/WS/0067]. The Committee provided a favourable opinion, with conditions in April 2017 (Appendix 6.2). The most significant of which was that the study must:

> "*Exclude from the study those patients who lack the capacity to make complex health and welfare decisions for themselves and have a Power of Attorney (PoA) or Welfare Guardian in place.*"

The protocol specified that it was anticipated that there would be individuals who had the capacity to consent to participate, but who lacked the capacity to make decisions about their health and welfare. It was viewed that this group could have valuable data about how individuals can express views and preferences and be involved in the process, despite not being the one making the decision. At the REC meeting, concern was expressed about the minority of cases in which individuals may disagree with the decision made, resulting in the potential for their participation in this research to cause unnecessary distress. This was offered by the Committee as the rationale to exclude this group of patients from participation. Less formal measures, such as allowing the clinical team to determine if patients were suitable to be approached, was not considered sufficiently robust. Revisions to the protocol and supporting documents were submitted and the study received approval to proceed on 26th April 2017 (Appendix 6.3). R&D approval was granted on 22nd May 2017 [2017/0123], allowing the study to commence recruitment in June.

In view of the narrowing of the study population, data were collected on the number of individuals at any time awaiting new care home admission, with specific count of those without capacity. This study provides the opportunity to better characterise 'capacity' within this population which will help to inform future research.

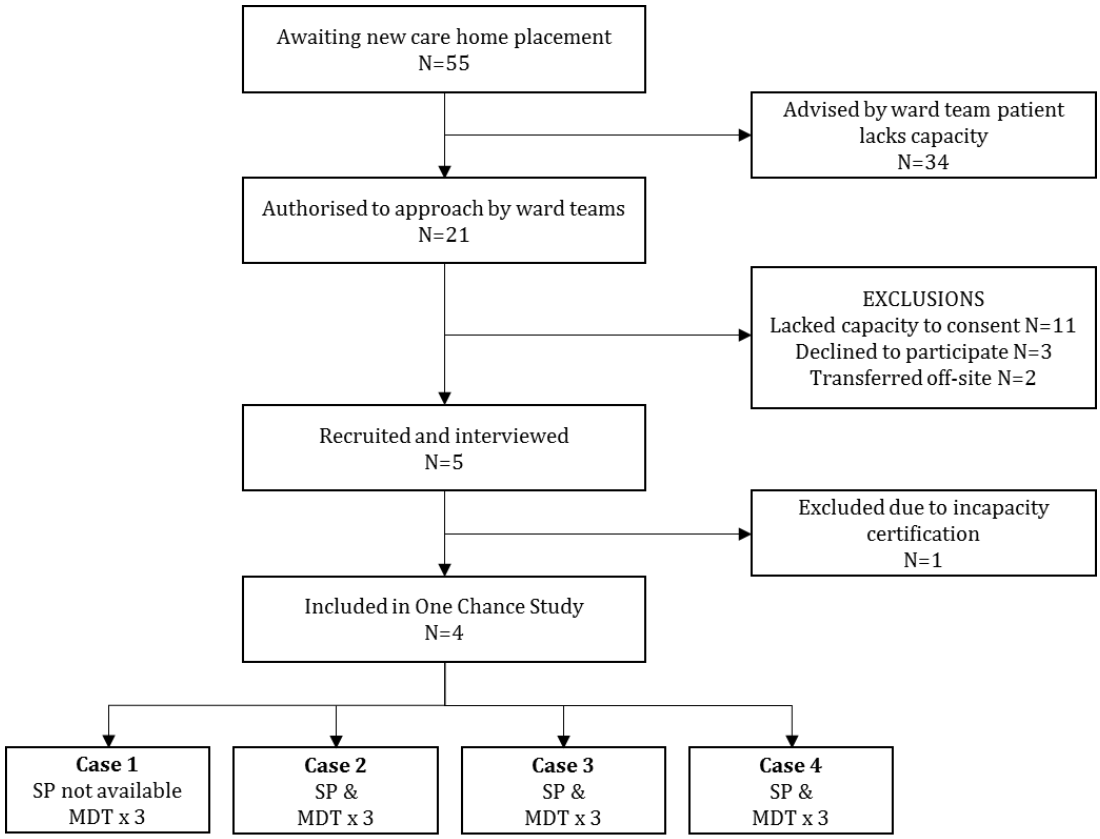
## 6.6 Results

The results section reports recruitment and findings from the Royal Infirmary Edinburgh (RIE) site only, as these are based on my own work.

### *6.6.1 Recruitment*

A total of 21 individuals were assessed for eligibility. Three declined to participate, two were transferred out of the RIE and 11 were not eligible due to incapacity to consent. Five patients consented and were recruited and interviewed. One had to be withdrawn as there was an active Certificate of Incapacity under Section 47 of the Adults with Incapacity (Scotland) Act Certificate, discovered at case-note review after interview. For the four eligible included participants, significant persons consented and were interviewed for three datasets and twelve interviews were conducted with the MDT, three for each dataset (**Figure 6.2**).

**Figure 6.2: Recruitment from the Royal Infirmary of Edinburgh**




*Footnotes: MDT – multidisciplinary team; SP – significant person*

### *6.6.2 Participants*

A short vignette is presented for the included dataset as an introduction (**Table 6.3**). Interviews were conducted with the individuals described in the vignette (Mr A – Miss E) and ward-based case notes were reviewed.

**Table 6.3: Dataset vignette**

| |
|---|
| Mr A is a 78 year-old gentleman who had two prolonged acute hospital admissions, totalling more than four months at time of interview. He has a history of two previous strokes. Prior to admission he lived alone and had no formal support. He was independent in his activities of daily living and out of the house daily using his mobility scooter. His next of kin was his nephew (Mr B), who lived outside Edinburgh and travelled with his work, resulting in infrequent contact with Mr A.<br><br>Mr A was originally admitted with a perforated duodenal ulcer and discharged home with a package of care. However, he was re-admitted three days later with diarrhoea and faecal incontinence which could not be managed at home. He recovered and commenced a period of inpatient care and rehabilitation, complicated by a wound infection and depression.<br><br>During his second admission, he was under the care of a Consultant Geriatrician (Dr C) and her ward-based MDT, including a Physiotherapist (Miss D). Miss D had met Mr A during his original admission. Admission to care home was first suggested by Miss D after discussion with other members of the ward-based MDT. Mr A was referred to the Hospital Social Work Team and appointed a social worker (Miss E) to support his discharge planning. |

### *6.6.3 Inductive thematic analysis*

Inductive thematic analysis of a single dataset identified nine major themes exploring how decisions are made to discharge individuals directly into a care home from the acute hospital setting: biography & personality; professional role; family role; limitations in local model of care; ownership of decision; risk; realising preferences; uncertainty of care home admission process; and psychological impact of in-hospital care.

#### 6.6.3.1 Biography & personality

This theme encompasses different perspectives critical to understanding Mr A. Biography was used to describe attributes emphasised by Mr A. Mr A's biography included his pride in having served in the military and how he perceived his worth in relation to occupation. He describes having his own "*regimental style*" and considers that he will be able to form relationships as "*the service connection lasts*". He distances himself from others who lack the experiences he has (Section 6.6.3.9). It is interesting that he frames his understanding of his current physical disability in the context of work:

> "*… but this has failed me I really feel I'm just, here for nothing now, well I am but I can't I'd never get a job. I've been struggling at home myself, and I can't cope*."(Mr A)

Purpose and self-determination feature in the narrative account he gives of his life and activities and are in keeping with the ownership he takes over the care home decision (Section 6.6.3.5). However, Mr A's inability to explain why he has the difficulties he faces are in keeping with a pervasive narrative of low mood and worthlessness:

> *"… who would want to go and talk to someone who's as pathetic as what you are*"(Mr A)

Miss D recognised in Mr A's personality a tendency for negativity and an under-appreciation of his own abilities:

> *"… he was very negative about himself, then he became very negative about the hospital and physiotherapy and he wasn't making any progress. A lot of his moods, and it was a lot of low mood, was, I think, his motivation*" (Miss D)

> "*… he's capable of so much more than he believes he is*"(Miss D)

The extent to which this view was formed from her earlier contact with Mr A, while a surgical inpatient, is unclear. Her advocacy for Mr A is explored further in Section 6.6.3.2.

Both Miss D and Mr B emphasise that Mr A values his independence:

> *"… he is an independent man and he really clings to that*"(Miss D)

> "*… he is very strong willed and, you know, you want him to live as normal a life as he can, so we were holding on the hope that he would recover*"(Mr B)

They seem to recognise this as a positive attribute and one which could potentially support him achieving his goals. Yet it is also seen as a marker of Mr A being different, needing to value independence and preserve it in spite of his physical disability.

#### 6.6.3.2 Professional roles

MDT participants were asked about their role and all presented a narrative of how they had been involved in Mr A's care and the care home decision. It was noticeable that team members were clear in what they considered a part of their role and that of someone else's, particularly for aspects to be dealt with by the Social Worker. This is further explored in Section 6.6.3.8. Noteworthy here was the contribution of Miss D, who acted outwith what she considered her usual role and became an advocate for Mr A within the hospital system. She had previously been involved in Mr A's care and describes the contrast in how she found him on his current admission:

> *"… he always gave 100 per cent. I was expecting the same, and I was quite shocked when he'd come here*."(Miss D)

She and her Occupational Therapy colleagues spent most time with Mr A and took time to understand what mattered to him:

> "*I'd asked him to prioritise what he wanted for his quality of life and I asked him, what was important for him to go home*"(Miss D)

Furthermore, when a move to an interim bed (with nursing care and remote medical oversight, but no therapy input) was proposed for discharge planning, she intervened:

> *"… so I phoned [hospital name] as a one-off to see if they would make an exception as a special case for [male name] and I explained his low mood and he was really kind of struggling in the ward and they said they couldn't, so I had to block that*"(Miss D)

Her intervention here suggests a disconnection in communication within the ward team in arranging an alternative which was not suitable for Mr A's needs. However, by attempting to seek an exception within the system demonstrates a flexibility to adapt to the local health care context. Ultimately it is Miss D who suggests a care home to Mr A, something she acknowledges she has never broached before and was concerned about:

> "*I was a little…not hesitant, I wasn't sure how well it would go down, and I didn't want to feel like I was giving up on [male name] either. I didn't want [male name] to feel like he was giving up, but I was quite glad when he was more receptive to it than I thought he would be, and I really did think it was in his best interests, not just for his safety but for his quality of life, that he wasn't alone at home*"(Miss D)

Miss D acknowledges this conversation is usually broached by medical staff, but that Mr A's therapy needs provided an opportunity to do this in a sensitive and supported manner. Her concern for his quality of life and personal fulfilment are notable. Interestingly, this extended advocacy role is not acknowledged by the other MDT members, Mr B or overtly by Mr A, who agrees his therapists played a part in his decision but prefers to present it as his own decision.

#### 6.6.3.3 Family role

There were two dimensions represented within this theme: the expectation of family assuming greater caring responsibility if Mr A were to return home and the tensions within this 'family' about the expected role of a nephew as next of kin.

One of the factors cited as influencing the MDT recommendation for care home placement was the lack of availability of family members to assume caring responsibilities:

> "*He had his…obviously his nephew who lived up north. Didn't have regular contact with him, but seemed to be supportive*" (Dr C)
>
> "*the nephew raised concerns that he wasn't around and he didn't live nearby. I think he works away, so he couldn't come and see him and take care of him as much as he'd like."* (Miss D)
>
> *"He was quite alone and normally there's a really supportive family and this is the last straw, that you've tried everything you can in the community and it just doesn't work and the family kind of help with that, whereas he has been quite alone and I think he has felt that.*" (Miss D)

Here, both the practical lack of availability of caring support and social isolation are identified as factors influencing professional decision-making. The implicit assumption is that, if Mr A had family nearby, they would have assumed a practical caring role. This is interesting given it had been identified that their relationship was not close.

Both Mr A and Mr B are open about their distant relationship:

> "*I've got no family but I have friends and extended family through marriage*" (Mr A)
>
> *"… but he's away on holiday quite a lot, no, no not holiday, he's a tour bus driver…. well he does my laundry, well his wife once a week. So he comes and visits me*" (Mr A)
>
> "*I generally have a difficult time from [male family member], he gives me a lot of grief*" (Mr B)

Despite the strains reported in their relationship, Mr B clearly cares for Mr A and expresses internal frustration about the role he should adopt. He reflects on how he might have acted differently had Mr A been his own father. Throughout the interview he expressed anger and frustration at the care provided to Mr A in hospital and the process of decision-making. However, he had a lack of outlet for these feelings due to this conflicted role as a more distant relative, supporting a capacitous uncle:

> "*I don't think that I have been given any credence or weight in any of this progress. If [male family member] had been my father I would have done something very different, but I'm not, because I've not got the wherewithal, the authority to override [male family member], I don't know if I would override my father, maybe that's the wrong phraseology, but I'm not...if [male family member] says, listen [name of interviewee], I don't want you doing that. If that was my father I would say, listen, well I couldn't care I'm going to do that anyway, if I think it was in his best interest."* (Mr B)

Mr B does not seem to disagree with the decision, rather with the way in which it has been reached and communicated. There appeared to have been no mechanism, which he was aware of, for Mr B to express these feelings and his comments indicated a high level of frustration.

#### 6.6.3.4 Limitations in local model of care

Interviewees highlighted several limitations in the current local system. Mr A was readmitted after just three days at home and this was a source of distress:

> *"… when I was sent home by the hospital"* (Mr A)

> *"The discharge I was against, and it was again a disappointing episode, I asked...they didn't discharge him, he was clearly unable to move, he couldn't walk ten yards to the toilet, ten feet to the toilet. I said, if they were going to discharge him he needed a care package. I asked any number of times for meetings. None of that happened, he was discharged with a care package, two visits a day that was woefully short."* (Mr B)

> "*So, that meant he had three days of horrific living… distressing and completely avoidable*." (Mr B)

They both considered this to be a failing on the part of the hospital, with a lack of care arranged at the time of his discharge. This remained an ongoing source of anxiety for Mr B, who was concerned this may happen again. This provides evidence that a 'failed discharge' impacts on the patient and their family, not just the healthcare system.

There was acknowledgement on the part of the hospital team that Mr A had to receive his rehabilitation in an acute hospital setting, due to a lack of local provision of post-acute care:

> *"… in an ideal world, you know, you'd send somebody to something like an intermediate care environment where you'd give them the time that they need to either get better or demonstrate that they're not going to get better. And that would be ideal, I think, but we don't have those facilities… we're very limited in what we do*."(Dr C)

This created a pressure with respect to the length of stay in the acute hospital. The therapy team reported this as a challenge in providing care, exacerbated by competing demands on their time:

> "*So there was a lot of pressure, people had been coming to morning meetings and things asking about [male name] and, could I not just send him home, and really [male name] in particular was quite picked out by people above, that's managers of beds and things, why is he still here?*" (Miss D)

> "*I'd have liked to have given him a lot more and spent a lot more time with him and take him to the gym…you have to prioritise your patients on discharge time, so he always is going to sit really quite low on the priorities, which is really frustrating for us because the reason he's here is for physiotherapy*." (Miss D)

Here the organisational factors appear to have affected the MDT, adding to pressure on them and reducing their professional satisfaction with the care they can provide.

An additional structural element was the limit on the usual availability of care in the community, which is capped locally at four visits per day. Alternative options (such as use of Direct Payments) were not mentioned by any of the interviewees or documented in Mr A's notes. Miss D worried this was an option which would not be consistent with Mr A's personality and goals:

> "*My concern was, knowing [male name], and knowing him for an extended period of time, he wouldn't want what that QDS package of care meant for him, which was only getting up when people came in, and it's just not really who he is*" (Miss D)

> *"… well, he physically could cope with a four times a day package of care, it's just he wouldn't want to, so it was more…a lot of the time it's you send them to a care home for their safety and because the family can't cope. Whereas, for [male name] it was more, yes, an element of his safety, but more his quality of life."* (Miss D)

This appeared to reflect the time Miss D spent working with Mr A and her evaluation of his preferences. She continually contrasted his circumstances with more common scenarios involving adults with cognitive impairment, having found Mr A's more challenging.

The final element of structural limitations was the model of Social Work involvement in care. Ward staff had initiated an early referral to Social Work, but Mr A was discharged from the Social Work caseload until he was considered medically fit to leave hospital, having completed his rehabilitation. Dr C expressed her frustration at the current system:

> "*So my attempt to involve Social Work early to pre-empt this obviously failed. And that is a shortcoming, I think, of social…of the Social Work department, because regardless, I saw somebody who was vulnerable, who was going to need a Social Worker, whether he was going home or anywhere else*" (Dr C)

This seemed to reflect a change in assessment processes meaning that Social Work cannot make assessments until all other care is complete:

> "*So if they're not at their base level, it's quite hard for us to decide and assess where they need to go after they leave the hospital*." (Miss E)

> "*… from a Social Work point of view, we can't progress both, you have to make a choice whether it's one or another. You can't sit and do both because they come from different budgets and you either go to a care home or you have a package of care."* (Miss E)

The narrative here seems to present a binary choice for individual patients and a lack of alternatives. It suggests a lack of scope for personalisation and flexibility around the individual and their needs. The lack of early involvement from specialists in social care can be problematic for healthcare practitioners, particularly given divisions between professional roles (Section 6.6.3.2) and awareness of the system (Section 6.6.3.8).

#### 6.6.3.5 Ownership of decision

Mr A considered that the decision had been his own and that he had been the one to initiate it:

> "*I'd to actually forward it myself, I got a visit from the Social Work, last week and asked me about what I'd like to do and said I'd like to do that so they've gone away and been trying to organise it for me"* (Mr A)

> *"… overall it was always coming to the fact I couldnae live by myself, back home, so it hit me it was the main option, which I agree"* (Mr A)

Although agreeing the therapists had played a part, the extent of discussions described by Miss D and the MDT documentation were not acknowledged by Mr A. The extent to which he takes ownership of the decision is interesting and contrasts with his often negative portrayal of himself and his character (Section 6.6.3.1). It is however consistent with his independence and self-determination in seeking order and resolution.

In contrast, while Miss D describes having gone beyond her role in suggesting a care home to Mr A, she reports relief at the decision he has reached:

> "*I've said to [male name], I would worry about you, once you were discharged I would kind of…he's one of those patients you lie in bed at night and you worry about them. I don't feel like that now that I know he's going where he can get some support"* (Miss D)

She does not seek credit for the decision, merely expressing satisfaction that he will be in a place where she considers his needs can be met.

Dr C distances herself from the decision which was made in her absence:

> "*… it was a joint decision, you know, staying…the physio and medical staff. It didn't seem unreasonable to me that that decision had been made. But I wasn't actively involved in making that decision*"

Throughout her interview she emphasises that Mr A's situation could have resulted in either discharge to home or to care home. While not in disagreement with the decision, it is interesting to note her perceptions of risk and decision-making compared with other colleagues (Section 6.6.3.6).

#### 6.6.3.6 Risk

The risks associated with care at home feature in the professional accounts. Miss E describes that part of the role of Social Work is in presenting risk to Mr A to allow him to make an informed decision:

> "*It's about laying out the difference of the choices between the two of them and what the risks are around for him. [Male name] himself was saying to me that he felt very scared and quite afraid of going home, which is a huge red flag for us, because we don't want someone going home scared because they're more likely to be tense, they're more likely to get into an accident if they're so tense, stressed out and worried*" (Miss E)

She and Miss D emphasise the potential risks associated with periods of time at home and the lack of available support. Mr A did not include risk or safety in his narrative about decision-making, instead with a focus on more positive reasons for his decision.

For Dr C, risk is an important consideration when making decisions about discharge:

> "*I think I'm very pro-independence and pro-home, so I do like…and I probably…I don't know how I fare against colleagues but I think that I…for that reason I probably take risk in discharging people home and that may be more than some of my colleagues. But I know from experience that often that is the best thing to do"* (Dr C)

It seemed to be important to Dr C to emphasise her usual approach. Understanding of risk and perceptions of its impact on decision-making were reflected in the literature, although the attitudes of medical staff were not formally explored.

#### 6.6.3.7 Realising preferences

As established in Section 6.6.3.1, having a history of association with the military was a source of significant pride for Mr A. During the decision-making process the suggestion of going to a care home which shared this military connection was raised, although it remains unclear how this arose. Mr A fixes on this, as a more acceptable form of help:

> *"… the only thing I think is that I just want. I'm happy to go to this military place, I'm not keen to go to the place from the local council, I would like to go to somewhere where I'd feel part of, part of the community rather than just being stuck somewhere*" (Mr A)

It is acknowledged by the MDT that this was a contributor to his decision-making and acceptance, having initially been reluctant to consider a care home:

> "*When he found out it was the Erskine, which is for veterans, he was a lot more interested...he was like, I've decided to go to a care home, and he was quite suddenly a lot more enthusiastic*" (Miss D)

> *"And he seemed much happier actually. Much more settled about what his future was going to be. And I think also because he is ex-service…not sure where he's ended up, but I think it was…which is the…whichever one, the care home that's just for ex-servicemen…"* (Dr C)

However, when Miss E was interviewed it was evident that, while a potential long-term option, it would not be possible for Mr A to remain in hospital waiting for this specific care home. This resulted in errors in communication among the care team:

> "*I don't know what's happened with this because when I got back from my holiday [male name] seemed to think he was on a waiting list waiting on a care home bed at Erskine and I'm not really sure why because it's only me or the family that can put him on the waiting list and I hadn't done that, and he hadn't filled out a form for it, so I'm not sure*" (Miss E)

> *"So I don't know if he's spoken to other ward staff and things have been chatted about further……he wouldn't have been allowed to stay in hospital to await the bed at Erskine, because it could be months, years, that a bed at Erskine would become available because it's a very popular care home"* (Miss E)

Critically, this appeared to have been a significant factor for Mr A in making his decision. Appreciating the significance of expressed preferences, particular where these have been generated by the care team, and realising these preferences is arguably essential.

#### 6.6.3.8 Uncertainty of care home admission process

Among the ward-based MDT there appeared a lack of knowledge of what would happen to this gentleman and how his admission to care home would be actualised:

> "*I don't think he really knows the steps and what happens, and it's not my area of expertise, I can't help him because I'm not entirely sure myself.*" (Miss D)

> *"I don't view it as…I don't feel confident enough, I don't know the details and I don't think it's my…necessarily my role to delve in to those details with them."* (Dr C)

There was honesty about this lack of knowledge and much was deferred to the Social Worker, who was considered responsible for this phase of care. Practical steps, including visiting care homes, having assessments by care home personnel were mentioned by interviewees, but there was uncertainty about them for Mr A specifically.

Mr B also reported being unaware of what was going to happen next and that Mr A had a right to know more:

> "*I don't think either of us know the next steps, what the route is, what the consequences of that are, the financial implications, never mind the medical or his wellbeing*" (Mr B)

> "*But, I think he should know more about what's happening to him. I think I need to know more about what's happening to him, but my needs shouldn't override his absolute requirement, and he doesn't know, and I don't think that's right*" (Mr B)

Although acknowledging their relationship is strained, the uncertainty here is concerning given the magnitude of the decision.

#### 6.6.3.9 Psychological impact of in-hospital care

Mr A had two prolonged hospital admissions where he received care in several areas of the hospital. He describes this as:

> *"… disconcerting, not knowing what you're in for what, where you are"(*Mr A)

Practical aspects of NHS care, such as moving between wards and the use of side-rooms on outlying wards for isolation purposes, have the potential to cause distress to the affected individuals. During the course of the interview it emerged that he found his experience of care in hospital to be isolating, particularly as many of the other patients had cognitive impairment. He feels this is having a deleterious effect on his own mental health:

> *"… it's beginning to get to me as well, I should get out and get back to normal thinking for normal people's brain. Cos I've got a good brain"* (Mr A)

Although there is a lot of activity in the ward, this lack of interaction troubles him. He distances himself from ward staff, due to their lack of common experience and emphasises his inability to communicate with the other patients:

> "*They're very busy, this ward's got 30 rooms in it and I'm in among a lot of nurses I mean a lot of them are just young girls and men, they've never had my experience and the people that I'm in, in my room as you see, not particularly contactable. I can't talk to them about anything.* " (Mr A)

He uses vivid imagery to emphasise the strength of his feelings about the potential harms from remaining in this environment for a long period of time, having determined that the care home environment will be more appropriate for him:

> "*I just hope, I just hope I manage to get into the area I want to go to, otherwise I've got to go somewhere and just like all, all those plants are quite well watered, I've not been as well watered as them and eventually will just, well you know what I mean, I can't risk it to die either mentally or physi*cally" (Mr A)

This social impact of a prolonged admission, particularly for someone who is cognitively intact, is an important insight which may not be detected without specific questioning and may influence decisions about future placement.

### *6.6.4 Case-note review*

Review of Mr A's ward-based case notes provided some documentation about how the decision for care home was reached. Miss D articulated her concerns about Mr A and the steps she had taken to seek advice from other members of the MDT. Miss D also documented the concerns Mr A raised and there is evidence of a preference to go home rather than to a care home. Miss E records her meeting with Mr A and Mr B and the decision agreed. On return from holiday Dr C notes that Mr A "*seems content with decision re: care home*". The case notes reflect the main factual steps in the process, but do not fully capture the views of Mr A or Mr B.

## 6.7 DISCUSSION

### *6.7.1 Key findings*

To summarise, Mr A's story is of a gentleman leading a comparatively independent life, with a degree of disability to which he had learned to adapt. He experiences a significant illness and period of deconditioning, which an MDT endeavours to support him to recover from. They are limited by the health and care system they are practising in and the lack of availability of post-acute care outwith the acute hospital environment. Miss D forms a particular connection with Mr A, going beyond her role to advocate for him and establish his priorities. She broaches care home as an option which she feels could provide him with a better quality of life than would be possible with care at home. Mr A adopts this narrative, persuaded by the idea of being surrounded by military comrades. Assessments and arrangements are initiated for discharge to care home, with uncertainty around how this will be realised.

Understanding the biography and personality of the individual would seem to be crucial elements in supporting them to make decisions. Miss D advocates for Mr A and it is unclear if this is due to empathy for him motivated by seeing his wider trajectory from a previous admission, the unusual nature of his circumstances and the extent of involvement or if this is usual practice. Empathy and compassion are attributes recognised as important among health and care professionals which should be valued (Jeffrey, 2016). It is difficult to be certain what influenced Miss D's practice as this was not specifically explored in the interview. It is important that achieving sustainably high-quality care for all does not rely on someone acting outwith their role and that the organisational culture and systems help facilitate staff to deliver best practice (Dixon-Woods *et al*., 2014). It is impossible to be certain what would have happened if Miss D had not raised care home with Mr A, but the subject may have been broached by other members of the team.

The different ways in which risk is portrayed and described are interesting. With some professionals seeking to avoid risk, while others are open about valuing a higher tolerance of risk in their practice. The absence of a patient or family perspective on risk is interesting. The interaction between shared phrases used by patients and staff around managing and coping and how these correspond to risk needs further evaluation. The expectation that family members, if present, would adopt a practical caring role is consistent with societal and policy expectations (Stewart, 2012), but may be problematic where relationships are less close and roles more uncertain.

The local organisation of health and care services is described by practitioners, with a very practical barrier in the lack of post-acute provision. Of note however is the limited role for social care professionals for individuals in hospital, through their lack of early involvement in the ward team and engagement only once a binary decision has been reached. This appears at odds with the following statement of what constitutes effective Social Work for complex older people which:

> "*… draws on distinctive aspects of the Social Work role – sensitive communication, moving at the individual's pace, starting where the client is, supporting the person through crisis, challenging poor practice, engaging with the individual's biography and promoting strengths and resilience*" (Kerr *et al*., 2005)

The psychological impact of hospitalisation, particularly for those who are cognitively intact is troubling. It is an area which can be overlooked with the primacy of physical health and rehabilitation and may influence an individual's decision-making. This insight was only identified from Mr A's account and not seen on review of his case notes or in the previous study.

### *6.7.2 Linking qualitative to quantitative findings*

The data presented in Chapter Five identified a very high prevalence of cognitive disorders among the population in hospital being admitted to care homes. The recruitment data support this, with 34 individuals considered by the ward team to lack capacity and a further 11 deemed to lack capacity to consent on researcher assessment. Some of those formally assessed as lacking capacity demonstrated fluctuations, highlighting the limitations of a single binary assessment of their status. Arguably therefore, it would be preferable to have assessed all potential individuals to ensure the same evaluation of capacity was made for them all. Section 6.5.9 describes the process of obtaining ethical approval for the study to take place. The original proposed design, including both those who have and who lack capacity to consent, fell outwith the criteria of the existing Scottish legislation. There was not sufficient research resource to attempt two parallel studies involving both those with and those who lack capacity to consent. Involving those with cognitive impairment and dementia in research is recognised to be challenging (West *et al*., 2017). There is a lack of consensus over how best to improve participation, while also protecting the rights of a vulnerable population (West *et al*., 2017). Those who lack capacity to consent to participate in research require a higher level of protection than those able to comprehend the risks. That said, it is important to find ways to ensure these individuals' views and preferences are represented in research designed to inform practice, so it has credibility and applicability to the complex in-hospital population.

There was evidence of involvement of the patient in the decision, although the nuances and full extent of the discussion were not captured in the ward-based case records. Although not able to recruit any individuals who lacked capacity, purposive sampling did seek to ensure those with dementia were included in the other datasets. Specific effort was also made to recruit and interview the Social Work staff involved in each dataset to address their absence from the previous study (Harrison *et al.*, 2017a). In this dataset, the Social Work role was demarcated from the rest of the ward-based MDT and this requires further exploration in the other datasets.

The methodology has enabled narrative accounts to be obtained, rather than the numerical approach reported in Chapter Five. This helps to bring the lived reality to these decisions and to explore the interactions between individual patients, their families and the staff involved in the decisions. Further links between the findings from the two projects will be established from completion of the analysis of all the datasets and application of the analytical frame (**Figure 6.1**).

### *6.7.3 Strengths & Limitations*

The study was successful in recruiting participants and those involved in their care to give their perspectives on this under-researched topic. The study has been conducted and analysed in

accordance with reference to accepted practice for qualitative health research (Green and Thorogood, 2011b). I have had the opportunity to support the study design and securing approvals; gain experience in participant recruitment and interviewing and; develop analytical skills within a supportive team of experienced researchers.

Coding the data inductively before application of the analytical framework was planned to reduce excluding potentially valuable insights prematurely (Dierckx de Casterlé *et al.*, 2012). The analysis presented, however, involves a significant amount of narrative and description as it is focused on a single dataset. Looking across all the datasets and reporting themes which are common or divergent will help to improve the depth of analysis presented here and allow for theory development and wider utility of the findings.

In common with Chapter Five, the findings highlight aspects of practice which may be specific to the region in which the studies have been conducted or to these specific patients and practitioners. This has the potential to limit their relevance and applicability to practitioners who have a different model of care.

There may be selection bias introduced, both from the patients who agreed to participate and that only a limited number of MDT participant views were sought for each. It may be that those prepared to tell their story and contribute to the study have different perspectives from those who declined to participate. Perhaps most significantly, participants could only be included in the study if they were assessed as having capacity to consent to participate. The vast majority of those in hospital awaiting new care home admission are not considered to have capacity, thus the insights from those who have capacity may not be applicable to that more vulnerable population.

## 6.8 CONCLUSIONS

The purpose of this study was to move beyond the numerical results reported in Chapter Five, to hear the voice of the patient and other stakeholders. Those voices begin to be represented here. That said, it would be wrong to assume that the thematic analysis presented can answer the question of how decisions are made to discharge someone directly from the acute hospital to a care home. Analysis of this dataset however, identifies a rich selection of themes which can be further explored in the other five datasets and using the analytical framework. This will help move from the in-depth account of a single dataset, to identify commonalities and divergence among the data and prior research findings. Thereafter the study findings will be reflected back to the wider literature in this area. The aim is to move towards generating findings which can be disseminated formally and used to inform local practice.

# PART THREE

# Harnessing Routinely-Collected Data

**Chapter Seven**
Health and Social Care Data Linkage: An Introduction

**Chapter Eight**
Methods to Identify Care Home Residents in Routinely-Collected Health Data

**Chapter Nine**
Using the Scottish Care Home Census to Explore New Care Home Admission Following Hospitalisation

# CHAPTER SEVEN
# Health and social care data linkage: an introduction

## 7.1 INTRODUCTION

This chapter will introduce the method of data linkage including its terminology, use in research and relevant governance structures. It will then describe existing health and social care data sources available to researchers in Scotland. It concludes by discussing the benefits and limitations of using linked data for research purposes. This chapter will introduce concepts which will be further examined in Chapters Eight and Nine, which describe the practical applications of using linked data for care home research.

## 7.2 DATA LINKAGE

Data linkage is the process by which records from different data sources about the same individual are brought together (Harron, 2016) in order to enhance the information available. For example, linking hospital admissions data to a disease registry, such as diabetes, allowed for analysis of prognosis after myocardial infarction among diabetic patients (Donnan *et al*., 2002).

Linkage of data from different sources requires repeated matching procedures which compare records to try to ensure that those which are being linked belong to the same individual (Kendrick and Clarke, 1993). The repetition is necessary because data may not match directly as the quality of the information can be affected by differences in recording, such as use of middle names, misspellings, name changes etc. (Kendrick and Clarke, 1993). One of the key requirements of data linkage is the presence of a variable which identifies each person in the data source as unique. This will be generated by the data scientists performing the linkage before the data are de-identified, removing personal identifying variables (such as names and full dates of birth) and then released to the researchers (Kendrick and Clarke, 1993). However, while use of names, dates of birth, postcodes and other values can be used to match individuals, using probabilistic matching techniques, if the data contain a unique identifying variable, this greatly assists the process and deterministic linkage can be performed (Harron, 2016). In this, the Scottish Community Health Index (CHI) number is invaluable. The ten-digit CHI number includes an individual's date of birth (DDMMYY) followed by a three-digit sequence and a check digit. This tenth value is always even for females and odd for males and is therefore unique for an individual (Information Services Division Scotland and NHS National Services Scotland, 2017a). The CHI itself is a population register and contains additional data about the individual which can be linked to other data sources (Womersley, 1996). Datasets which record CHI can therefore be more readily matched together, with greater certainty that the records all belong to the same individual.

There is recognition in data linkage methodology that some records will be incorrectly linked (Harron, 2016). Therefore, those performing linkage have to determine acceptable rates of error and are likely to require manual review of indeterminate cases (Harron, 2016). Understanding

the limitations of the data sources is vital when interpreting and applying the findings in practice.

### *7.2.1 Terminology*

There is a range of potential data sources available to researchers and practitioners in Scotland for data linkage, it is important therefore to have an overview of how these are described and collected.

**Routinely-collected health and social care** data describe the data generated by the everyday interactions of an individual with health and social care services. This might be through the dispensing of a prescription, attendance at an outpatient clinic or issuing of a community alarm. These data are recorded by health and social care practitioners as part of their everyday activity.

The term **administrative data** is used to describe the information generated by interactions with other agencies, such as education, housing and the criminal justice system. Again these data are recorded as part of existing professional practice and help to generate national statistics. Their potential for social research has been recognised and there is work under way nationally to link these data across sectors to develop understanding, including a linkage between education and health data across Scotland (Wood *et al*., 2013).

Both health and social care data and administrative data are distinct from **population surveys**, such as the Scottish Health Survey (SHeS) or the National Census. The SHeS was first collected in 1995 and has been annual since 2008, aiming for a geographically diverse sample of the Scottish population (Brown *et al*., 2016). Data are collected from face-to-face interviews with adults and children living in non-institutional care settings on a range of known risk factors and disease conditions prevalent in Scotland (Brown *et al*., 2016). To add value to the data collected in the SHeS, responses have been linked to hospitalisation data to review the associations between risk factors and disease outcomes (Hanlon *et al*., 2007). Such research shows the potential for data linkage to improve understanding of the distribution and determinants of disease within the population (epidemiology). The National Census, held by National Records for Scotland, is a decennial data collection which should include all those living at a residential address, including in institutional care, in the country (National Records of Scotland, 2017c). It contains data on household structure and there are specific questions for each individual living in the household. A five per cent sample of the census (approximately 270,300 people) has been identified and their data further linked to other sources to construct a population sample known as the Scottish Longitudinal Survey (SLS) (National Records of Scotland, 2017a). SLS data can be made available for research (Scottish Longitudinal Study Development & Support Unit, 2017).

The computing science term **'big data'** is increasingly associated with health and care data (Murdoch and Detsky, 2013). The Information Commissioner's Office acknowledges the difficulties in defining 'big data' and that no single agreed definition exists, the term is typically applied to data which are considered challenging (due to size, format, etc.) to analyse using established analytical methods (Information Commissioner's Office, 2017). This lack of clarity can be problematic as data can be considered 'big' depending on the skills and experience of the user. Many cohort studies or data linkage projects can be considered as using 'big data'. Big data have great potential to influence patient care, but increasingly rely on using analytical

techniques, such as machine learning, to manage the volume of information; natural language processing to interpret and; use free-text recordings and systems to allow data to be analysed in "*real time*" (Murdoch and Detsky, 2013).

### *7.2.2 Using linked data for research*

Data linkage research using routinely-collected health and social care data takes data which have been collected without the express consent of individuals. This sets it apart from other research methodologies and raises important ethical questions for researchers and ethics committees. The Nuffield Council on Bioethics identified that use of data in research has the potential both to benefit and to harm and that our understanding is limited because we cannot anticipate many of the potential consequences, due to lack of knowledge of the data and the future uses which technology may allow (Nuffield Council on Bioethics, 2015). It makes seven practical recommendations about how data linkage should be approached (**Table 7.1**):

**Table 7.1: Recommendations for approaching data linkage research** (Nuffield Council on Bioethics, 2015)

| |
|---|
| 1. Identify prospectively the morally relevant values and interests.<br>2. Take special care to identify those interests that may be especially at risk or that arise from diverse values.<br>3. Do not rely simply on compliance with the law to secure that data use is morally appropriate.<br>4. Establish what existing privacy norms are engaged by the contemplated uses of data.<br>5. Involve a range of those with morally relevant interest in the design of data initiatives.<br>6. State explicitly the set of morally reasonable expectations about the use of data.<br>7. Involve a range of those with morally relevant interest in the continuing governance and review of data initiatives. |

These principles instil the value of effective governance of data linkage research and conduct supported by public engagement and understanding. Explanation of how data linkage research is conducted and the separation of researchers from access to identifiable data can help to allay public concerns about such work (Xafis, 2015). However, the *care.data* project in NHS England, which was intended to extract data from primary care records unless individuals opted out, had to be suspended due to the controversy expressed by the public (Carter *et al*., 2015). The authors argue that the reasons for the failure were that the project did not secure "*a social licence*", with concern that the project had not been demonstrated as being for the good of the public and also about how the data were to be used (Carter *et al*., 2015). In contrast, the Scottish research register 'SHARE' project has been more accepted and has recruited 130,000 individuals since its creation in 2011, with participants allowing their existing data held by the NHS to be used for relevant research studies (McKinstry *et al*., 2017). These examples provide important lessons for all researchers considering the use of routinely-collected data and the imperative for value to be demonstrated and privacy assured.

The 2016 Caldicott Review of data security and uses in NHS England highlighted that public awareness around the collection and use of their health and social care data was surprisingly limited (National Data Guardian for Health and Care, 2016). It concluded that although there is a recognition of the need to share data to enhance the quality of care and research, this should be

conducted mindful of the interests of the individual, ensuring personal confidential data are protected (National Data Guardian for Health and Care, 2016). Fulfilling the aspirations and needs of researchers and ensuring that individuals are protected requires careful balancing and there are ways to reduce and manage risks. Laurie *et al.* propose "*an adaptive governance model*" which recognises that different models of delivering data linkage have developed across the UK and that our understanding and capabilities in this field are continually changing (Laurie *et al*., 2015).

### *7.2.3 What governance and organisational structures exist to facilitate data linkage research in Scotland?*

Scotland has developed a Data Linkage Framework for research and statistical purposes which governs the production of national statistics, longitudinal research resources and specific individual research projects (Scottish Government, 2012). The principles of the Framework include the need to ensure that: the research is in the public interest; that there is an accountable governance structure; that risks to privacy are mitigated by use of anonymisation and data security measures and; that access to data is restricted to approved individuals (Scottish Government, 2012).

The Public Benefit and Privacy Panel for Health and Social Care (PBPP) was formed in May 2015, merging approvals processes for data linkage research in Scotland (NHS National Services Scotland, 2016a). This centralisation of approvals aimed to help to streamline the application processes for data linkage, in recognition that researchers were often applying to multiple sources for the data for a single project (Brett and Deary, 2014). Not only was the process inefficient and time-consuming, there were also inconsistencies in assessment between data controllers (Brett and Deary, 2014). The specifics of applying for permissions to use linked data will be discussed later in Chapter Nine. The PBPP is central to ensuring the principles of the Data Linkage Framework are upheld by researchers wishing to use health and social care data.

The 'Scottish model' for conducting data linkage research has taken time and consultation to develop (Pavis and Morris, 2015). It uses 'The Five Safes' principles (**Table 7.2**) to help facilitate safe data linkage research.

**Table 7.2: The Five Safes** (adapted from Pavis and Morris, 2015& UK Data Service, 2015)

| Safe | Explanation |
|---|---|
| Safe project | The project must be of public benefit and be scientifically and ethically sound. |
| Safe people | Only approved researchers who have undergone specific training and signed user agreements are allowed access to the data. |
| Safe data | Data have been de-identified to remove names, full dates, addresses etc. but the data which are available are confidential. |
| Safe settings | Access to data is restricted and uses 'secure settings', such as Data Safe Havens, which can be accessed in specific locations or using remote access through virtual private networks. Security procedures are high. |
| Safe outputs | All results and outputs from analyses are checked by independent staff to ensure that individuals cannot be identified and the results the researcher can use maintain privacy, this process is called statistical disclosure control. |

The electronic Data Research and Innovation Service (eDRIS) has been developed to support researchers in applying to use linked data, co-ordinating the extraction and linking of the data, data provision *via* secure platforms and statistical disclosure control (Pavis and Morris, 2015). Additional supportive infrastructure is provided from the Administrative Data Research Centre (ADRC), the Farr Institute and the Scottish Informatics and Linkage Collaboration (SILC) (Hagger-Johnson, 2016).

## 7.3 HEALTH AND SOCIAL CARE DATA SOURCES IN SCOTLAND

### *7.3.1 Health data sources*

Scotland benefits from a robust system of national health data collection which spans from antenatal care records through to death registration and attempts to capture significant health events throughout an individual's life. Most healthcare in Scotland occurs as part of the NHS and thus use of NHS records is thought to be representative of routine healthcare. The national statistics provider in Scotland is the Information Services Division (ISD) of NHS National Services Scotland (NHS NSS) and it is responsible for collection and storage of these data sources. The National Data Catalogue online provides data dictionaries which identify the way data have been coded and a list of all the national datasets held by ISD (Information Services Division Scotland and NHS National Services Scotland, 2017e). These data include the Scottish Morbidity Records (**Table 7.3**); disease registries; prescribing data and hospital activity statistics which include data from accident and emergency, GP out-of-hours, urgent care, waiting times and delayed discharges (Information Services Division Scotland and NHS National Services Scotland, 2017f).

**Table 7.3: Scottish morbidity record data held by ISD** (Information Services Division Scotland and NHS National Services Scotland, 2017f)

| Scottish Morbidity Record (SMR) | Data available | Years data are available |
|---|---|---|
| SMR00 | Outpatient appointments & attendances | 1997 – present |
| SMR01 | General acute inpatient & day case | 1960 – present |
| SMR02 | Maternity inpatient & day case | 1975 – present |
| SMR04 | Mental health inpatient & day case | 1981 – present |
| SMR06 | Scottish cancer registry | 1958 – present |
| SMR25 | Scottish drug misuse database | 1996 – present |
| SMR50 | Geriatric long-stay | Discontinued 2011 and merged into SMR01 |

These health data can be used to identify trends and compare performance between areas, for example the regular publication of statistics about delayed discharge are reported at Health Board level. Published data are fully anonymised, including the aggregation of data which describe rare conditions or small numbers which could lead to individuals being identified. The data are held in ISD with appropriate safeguards and personal identifiers are stored so they can be used to link data sources together for approved research projects to help investigate more specific questions on a defined population. The vast majority of these sources, however, reflect use of secondary care services, aside from prescribing data which are primary-care based. Reliance on these sources will underestimate the prevalence of long-term conditions which are better recorded in primary care data (Information Services Division Scotland and NHS National Services Scotland, 2008). In the longer term, primary care data should become more readily available as part of the Scottish Primary Care Information Resource (SPIRE) project which commenced formally in 2017 (NHS National Services Scotland and Scottish Government, 2016).

### *7.3.2 Social care data sources*

Although Scotland has an established tradition in using routinely-collected linked health data to explore practice and improve patient care, using social care data for this purpose is comparatively new and underexplored. Some of the challenges within social care data are the same as with health data, i.e. time required to link data, quality and availability of data, variables collected as part of everyday practice (Taylor and Lynch, 2010). Analysis of English social care data suggests data quality issues are much greater than those found when using health data, although the authors suggest that this could be addressed in part by linking the two, to maximise their usefulness (Kemm *et al*., 2010). A pilot social care data linkage project conducted in NHS Tayside found that although the work was feasible, methods of documentation, recording culture and understanding of variables were challenging and required high levels of joint working to help understand the organisational cultures and practices (Witham *et al*., 2015). The time required to build and maintain these relationships is not to be under-estimated (Witham *et al*., 2015). These issues were echoed in a stakeholder meeting of health and social care practitioners and researchers across Scotland who formed a list of potential opportunities for linked health and social care data, but also identified important barriers, including consent

for sharing data and the skills and expertise required to analyse such data (Atherton *et al*., 2015).

As part of wider efforts to support Health and Social Care Integration, the Scottish Government has commissioned NHS NSS-ISD to work with Local Authorities, NHS Boards and the Scottish Government in the Health and Social Care Data Integration and Intelligence Project (HSCDIIP) (Information Services Division Scotland and NHS National Services Scotland, 2014). One of the key aims of HSCDIIP is to develop linked, shared databases containing individual-level anonymised data to evaluate interventions, policies and secular trends which can be analysed centrally to allow comparisons between areas (Information Services Division Scotland and NHS National Services Scotland, 2014).

The Social Care Survey has been collected annually by the Scottish Government since 2013. This collates the data from all Local Authorities based on use in a single census week (Scottish Government, 2017c), so provides a snapshot of use (**Table 7.4**). The other major national source of social care data in Scotland is the Care Home Census (**Table 7.4**).

**Table 7.4: Social care data sources in Scotland** (Information Services Division Scotland and NHS National Services Scotland, 2016a, Scottish Government, 2017c)

| Data source | Data available | Years data available | Data controller |
|---|---|---|---|
| Social Care Survey | Home care (demographics, reason for care provision)<br>Community alarms<br>Telecare<br>Self-directed support | 2013 onwards for these variables<br>Home care data collected since 1980s | Scottish Government |
| Care Home Census | Aggregate data on care homes, funding, number of places, length of stay, admissions, discharges etc.<br>Individual-level resident data on long-stay admissions | Data collection commenced in 2003.<br>Personal identifiers collected since 2012. | Information Services Division & Scottish Government |

Unlike the Social Care Survey, the Census aims to capture all activity in the care home throughout the year, returned on an annual basis, although the completeness of these data has not been formally assessed. Both resources are having the CHI added to them in 2017 to help to facilitate linkage with other routinely-collected data sources. Results from both data sets are published as annual reports, reporting trends with summary data available online. These data are aggregated and grouped to prevent identification of individuals in small-area geographies or with rare conditions necessitating social care.

## 7.4 WHAT ARE THE POTENTIAL BENEFITS AND LIMITATIONS OF USING LINKED DATA IN RESEARCH?

### *7.4.1 Benefits of using routinely-collected linked data*

One of the six 'guiding principles' embedded in the Chief Scientist Office (CSO) Research Strategy for health and social care in Scotland is to:

> "*Exploit our ability to link information from health, social care and non-health sources using data to support better treatment, safety and research*"(Chief Scientist Office and NHS Scotland, 2015)

This acknowledges the strategic importance and potential of data linkage as a research methodology. The perceived benefits of using data are predicated on the ability both to obtain access to data sources which are representative and complete and to link these reliably to other robust data sources. The benefits discussed by the CSO are based on successful projects which have been conducted, extrapolation of these to other aspects of health and care will necessitate these conditions being fulfilled.

One of the major advantages posed is the **evaluation of 'real' people and their experiences** and interactions with the health and care system by using routinely-collected data sources. As this approach is inclusive and does not rely on individual consent or participation beyond use of services, this allows for variations to be identified, particularly among groups who may be under-represented in data derived from clinical trials. Evidence generated in clinical trials may be subject to biases due to the non-inclusion of specific groups. Historically these have been those who are older and female (Lee *et al*., 2001), but have also been those from different racial or ethnic groups (Murthy *et al*., 2004) and those with cognitive impairment (Taylor *et al*., 2012). The creation of the Scottish Health and Ethnicity Linkage Study brought together data from the Census with health data to try to explore the role of ethnicity on various health outcomes (Bhopal *et al*., 2011). This has helped to generate evidence of variation in outcomes between groups, which has stimulated targeted research to inform practice (Bhopal *et al*., 2011).

Secondly, data linkage allows the **evaluation of complex interventions**, such as changes in policy, by conducting population-based epidemiological studies at scale. The evidence generated to evaluate the impact of smoke-free legislation has demonstrated convincingly the impact of this legislation on health outcomes in a much broader way than would have been possible by clinical studies on groups of individuals. By way of an example, researchers evaluated trends in asthma admissions among school-age children, a group which may not have been anticipated to be affected and found evidence of an association with reduced respiratory disease (Mackay *et al*., 2010). This approach offers the potential to evaluate social policy interventions (such as housing) and the impact of legislation, to generate evidence based health and social care policy, ensuring knowledge of both effective and ineffective interventions are recognised, shared and acted upon.

There may be a role for data linkage to enhance the value of past or current clinical trials. A comparison has been made between the evaluation and recording of trial end-points using routinely-collected data in comparison with those collected within the trial, with good levels of agreement found (Barry *et al*., 2013). This approach may be of particular value when evaluating **long-term outcomes,** such as the development of dementia or mortality, beyond that within the

scope of the trial itself. The West of Scotland Coronary Prevention Study (WOSCOPS) is one such trial, the value of which has been enhanced by using data linkage for longitudinal follow-up. Linking of the participants in WOSCOPS has produced long-term hospitalisation and mortality data and also enables evaluation of compliance and its effects on outcomes (Ford *et al*., 2007).

Routine data have the potential to be **inclusive sources**, but this must be evaluated formally as it is possible that individual sources may not be comprehensive. Early work done in Tayside evaluated the completeness of multiple sources of diabetes diagnostic information and found that data linkage was more sensitive than the use of individual sources, such as primary care records, as it identified patients who had received care across primary and secondary care services (Morris *et al*., 1997). Importantly, this work also quantified the completeness of the individual data sources and identified those which were most valuable (Morris *et al*., 1997), which provides helpful information for other researchers.

Finally, it is argued that routine data should be used to **inform resource allocation** within the care system, integrating real-world data obtained *via* data linkage to help to predict the needs of the population (Dixon and Bardsley, 2012). Although this would seem to be a fairer and more pragmatic approach, a better understanding of our data sources and skills in using them is likely to be necessary before this can be achieved at scale and in real time.

### *7.4.2 Limitations of using routinely-collected linked data*

One of the greatest concerns in using routinely-collected data is the issue of **data quality and completeness**. By their nature, routinely-collected data are those which are generated by the everyday use of health and social care services. Systems for data entry have been created for the delivery of care and monitoring of specific metrics of interest to the service collecting the data. In the case of hospital records, these are based on data from clinical case notes and ward-based systems of recording. These data are evaluated by clinical coders and used to generate national hospital records, such as SMR01. Inaccuracy and incompleteness of recording by clinicians (often the most junior staff) affects the value of the clinical coding (Medford, 2013) and hence the value of these data. That such data are used for the generation of national statistics, service evaluation and research may not be appreciated by those entering the data. A key responsibility of researchers is to ensure findings are shared with those who have collected the data.

Researchers using linked data must be aware of **changes in practice** for recording and coding over time. This may include changes in data sources, such as the cessation of ICD-50 (**Table 7.3**), changes in the version of International Classification of Diseases (ICD) codes used for diagnostic coding and changes in coding practice, such as the inclusion of 'hospice' as a separate place of death (Davies *et al*., 2016). Policy interventions, such as the UK National Dementia Strategy, can also influence practice, with data showing increased rates of dementia diagnosis following the strategy introduction (Donegan *et al*., 2017). These changes could be mistaken as representing a change in the underlying prevalence of the disease, rather than reflecting the effects of policy on practice.

Furthermore, the data which are available for use are **restricted to those measured** by the system. Additional work is required by the researcher to understand their meaning, ideally with reference to the coding system used to create them. If these are available, such 'meta-data'

provide a dictionary by which users can ensure they are interpreting the data as intended. Researchers may, however, wish additional information or for the collected variables to have been categorised differently. Linkage to other sources may increase the information available, but may also introduce the possibility of conflicting information on the same individual, such as their residency status. As with any analysis, the potential for bias arises depending on how researchers treat such information and there is an imperative to be honest about the decisions made in analysing 'real' data. These challenges support the need for data to be analysed and interpreted as part of a research team, combining content expertise from practitioners with data expertise in analytical methods.

## 7.5 CARE HOME RESEARCH USING LINKED DATA

Using routinely-collected linked health and social care data for care home research has huge potential. Care home residents are recognised as a population in which recruitment is challenging due to the high rates of cognitive impairment, lack of availability of those to provide proxy consent and the need to ensure research is sensitive to a care home being a person's home, rather than a clinical facility like a hospital (McMurdo *et al.*, 2011).

The ultimate aim would be to have data which are sufficiently complete and robust to allow research on the care home population across Scotland to be conducted at this 'macro' level. This would offer the potential to characterise the population as never before and to help identify variations in care, service use and practices which can then lead to focused and specific research using alternative methods. Before this aim can be met, however, the accuracy, validity and completeness of the data must be explored and defined.

# CHAPTER EIGHT
# Methods to identify care home residents in routinely-collected health data

## 8.1 BACKGROUND

The rationale for identifying those living in care homes has been outlined (Chapter One, Section 1.9). Briefly, it is a necessary way to describe the needs and service use of a vulnerable and complex population. New care home admission can be an important outcome measure for healthcare services. Care home residents are under-represented in data research (Moore and Hanratty, 2013). Although there are several health data sources which contain variables about residency, their accuracy has not been formally described. This Chapter outlines why and how identifying care home residents in routine health data is challenging, before presenting analyses of linked health data from NHS Fife and NHS Tayside as evidence.

### *8.1.1 What is known about the quality of routine health data sources?*

Routinely-collected health data in the UK are thought to have a relatively high rate of accuracy for diagnoses, although they are known to be incomplete (Burns *et al*., 2012, Campbell *et al*., 2001). The inpatient and day-case Scottish Morbidity Record (SMR01) has previously been evaluated with respect to accuracy of stroke diagnosis (Davenport *et al*., 1996, Turner *et al*., 2015) and vascular surgical procedures (Raza *et al*., 1999), showing omissions in case ascertainment when compared with national audit data and case-note review. There are no published validations of the accuracy of SMR01 data in determining care home residency.

National evaluation data from a sample of 24 acute hospitals on the quality and completeness of the SMR01 fields 'admitted/transferred from' and 'discharged/transferred to' indicated that these were only correctly completed in 61-67% of cases across Scotland in 2011 (Information Services Division Scotland and NHS National Services Scotland, 2012). However, this evaluation found that the accuracy of these data is highly varied (15-98%) across different hospital sites (Information Services Division Scotland and NHS National Services Scotland, 2012).

Researchers in England have also experienced difficulties in identifying care home residents in hospital admissions data, with hospital coding of admission source insensitive (Housley *et al*., 2018) and postcode linkage misclassifying non-care home addresses (Godden and Pollock, 2001). The Nuffield Trust conducted analysis based on postcode areas which included a single care home registered with the regulator, the Care Quality Commission, but this also necessitated exclusion of small care homes to reduce potential misclassification (Sherlaw-Johnson *et al*., 2016). These cases identified deficiencies in the recording of residency data at the level of secondary care systems which had significant potential to lead to erroneous results if used for monitoring, for example the source of hospital admissions.

### *8.1.2 What contributes to complexity in assigning residency status?*

The complexity of assigning residency status arises from several related factors. These can be broadly divided into those concerning the available data sources and factors specific to care homes (**Table 8.1**).

**Table 8.1: Factors contributing to the complexity of assigning residency status**

| **Data source complexity** | |
|---|---|
| SMR01 | Hospital admission and discharge data do not contain patient address details. Instead, these records contain two fields of potential interest: 'admission/transfer from' and 'discharge/transfer to', which are numerically coded.<br>The admissions field has 45 codes and the discharge field has 61 codes (Codes 20, 25, 28 & 29 can be used to identify care homes)(Information Services Division Scotland and NHS National Services Scotland, 2017g). |
| Community Health Index (CHI) | CHI records contain address details and are updated whenever an individual's address changes based on their Primary Care record. A change is triggered by a patient notifying their GP of a change of address or by a change of GP practice as a consequence of moving. Updates to CHI may reflect a genuine change of address, but will also detect small changes in format and abbreviations e.g. Road to Rd etc. This makes CHI a highly sensitive source of changes in address, which has to be checked to identify genuine changes. |
| CHI Institution Flag | The CHI record also contains an institution flag. Addresses which are classified as 'institutions' (including prisons, universities, schools and care homes) have a range of alphanumeric and numeric codes assigned to them. This includes code 93 (residential home) and code 98 (nursing home) to correspond to addresses which are residential or nursing homes respectively. The accuracy of this flag has not been formally assessed. |
| Anonymised data provision | A key aspect of using anonymised linked data for research is the removal of identifiable variables before data are released to researchers. Therefore, there are seldom opportunities to verify address data, relying instead on coding. Comparing coded flags with the underlying address data requires access to these variables. |
| **Care home complexity** | |
| Defining what is a care home | Identifying care homes requires a formal source, as they are not nationalised organisations and a definition of the level of care they provide should be included. |
| Multiple uses of care home beds | Care home beds are also used for temporary placements, including respite care, assessment and step-down services. Individuals receiving this care are not permanent care home residents and so for analysis purposes they should be differentiated from long-stay or permanent residents as they are a distinct population. |
| The care home market is dynamic | Care homes may not be permanent providers of care. Some care home addresses may be residential properties before or after being a care home. Some will only become a care home after a specific date, others stop being a care home if they close. The market is dynamic, with other care providers taking over existing care homes and the name being changed, although both building and residents are unchanged. Identifying 'care home addresses' is thus date-sensitive. Changes must be registered with the Care Inspectorate, which holds a list of care homes and their 'active' dates. |

There is potential for bias in the ascertainment of care home residency as an outcome measure. Individuals who have contact with healthcare services are more likely to be identified by methods which use health data than those who do not. If these are based around a common factor, such as medication prescription or change of GP registration, such change may be reflected sooner than if it were reliant on hospital attendance or admission. There may be a delay in an individual's change of address being reflected in routine data sources, the duration

of this delay is unclear. It is likely to affect the accurate identification of residence-based outcome assessment measures.

Alternative data-driven approaches, such as identifying residences of multiple adults aged ≥75 years are potentially unreliable. 26% of care homes in Scotland are not for older people and it is likely that approaches based on age will not identify care homes which are home to those with learning disabilities and mental health problems (Information Services Division Scotland and NHS National Services Scotland, 2016a). Similarly analyses based on identification of household size is possible, but risks missing small homes (< ten beds) which may provide specialist care.

Having outlined the challenges in identifying care home residents in routine health data this Chapter now illustrates this with analyses of data.

### *8.1.3 The Older Person's Routine Acute Assessment Project*

The Older Person's Routine Acute Assessment (OPRAA) Project is a prospective cohort study of adults aged ≥65 years admitted to the Victoria Hospital, Kirkcaldy in NHS Fife. Data were collected as part of routine clinical care in the Acute Medical Unit (AMU). OPRAA included evaluation of cognitive function, functional performance and social circumstances. These data have been linked to routine health data to facilitate evaluation of outcomes (Reynish *et al.*, 2017).

Analysis of the OPRAA incident cohort is part of a National Institute for Health Research-funded study: 'Understanding the outcomes of people with cognitive impairment and/or dementia admitted to the general hospital'(NHS National Institute for Health Research, 2015). The primary outcome was whether the person was living at home (defined as a residential address, not a care home) 30 days after discharge. One of the secondary outcome measures was new care home admission at hospital discharge. Calculation of these outcomes required a robust method to identify existing care home residents on admission and to identify new care home admissions at discharge.

### *8.1.4 Health Informatics Centre*

The Health Informatics Centre (HIC) holds routinely-collected data sources for the populations of Fife and Tayside and can link these to research data, providing de-identified data *via* a secure Safe Haven environment to conduct research (University of Dundee, 2017). The analysts within HIC have access to identifiable data, including full address information with postcodes, thus permitting comparison between flags and codes within the data and the address data, which are not released to researchers.

### *8.1.5 Project role*

I was one of two people who provided independent classification of lists of addresses (the other was Professor Bruce Guthrie [BG]). I contributed to the planning of alternative methods of address allocation. All admissions data for the OPRAA cohort were provided by HIC and linked by the OPRAA project statistician. I adapted SAS syntax to perform the linkage of the HIC

address-labelling variable with the admissions data, to analyse the performance of SMR01 on admission and discharge for care home residency. I combined the results of our address classifications, matching them to institution flag data.

## 8.2 AIMS

There were four aims underpinning the work presented in this Chapter:

**Aim one**: to evaluate methods to identify care home residents in routinely-collected health data, to develop an address-labelling variable to indicate whether the address is a care home or not;

**Aim two**: to apply the address-labelling variable as a reference standard to the OPRAA incident cohort and check its accuracy;

**Aim three**: to determine the accuracy of the SMR01 admission and discharge coded variables in the wider OPRAA admissions cohort;

**Aim four**: to determine the accuracy of the CHI Care Home Flag using additional cross-sectional data from NHS Fife and NHS Tayside.

## 8.3 METHODS

### *8.3.1 Inclusion and exclusion criteria*

A 'care home' was the term used to describe a nursing or residential care facility in Scotland providing 24-hour care for residents. The source used to identify these institutions was provided by the national regulator of care services, the Care Inspectorate, which provided a list of all registered facilities which it inspects. This list is updated biannually and includes historic data on services which are no longer active, including their dates of service provision. Registration with the Care Inspectorate is mandatory. Services providing sheltered housing, supported accommodation and extra care housing were excluded.

### *8.3.2 Data sources & definitions*

- Community Health Index (CHI) register – master list of changes to address details
- Scottish Morbidity Record 01 (SMR01) – inpatient hospital admissions, discharges and day-case records
- OPRAA admissions cohort – all SMR01 records between 2008-2016 for individuals aged ≥65 years who were admitted to the AMU in the Victoria Hospital Kirkcaldy
- OPRAA incident cohort – first emergency admission of adults aged ≥65 years admitted to AMU between 1st January 2012 and 31st December 2013 who had not been admitted to AMU in the previous six months
- CHI Institution flag – a flag which is applied to all CHI records where the address is an institution. This incorporates specific codes for residential homes (Code: 93) and nursing homes (Code: 98). These flags are collectively known as the 'CHI Care Home Flag'

### *8.3.3 Preparatory methods to create the HIC address-labelling variable (Aim one)*

#### 8.3.3.1 The master CHI register

The CHI is the national patient identifier used in NHS Scotland (Womersley, 1996). The master CHI register records the CHI number, address and the date the address is valid from, together with the Health Board of residence and the CHI institution flag, where appropriate. Individuals may have multiple rows in the register if their address data have changed. Updates to the CHI register for residents of Tayside and Fife are sent to HIC monthly. All CHI records for the individuals in the OPRAA admissions cohort were extracted for use in these analyses.

#### 8.3.3.2 HIC address-labelling variable

The objective of the first part of this work was to label each record from the CHI register with the binary classification of: 'care home address' or 'not a care home address'. The purpose of this classification was to generate the HIC address-labelling variable. By labelling each address, this variable could then be linked into the data to identify who was a care home resident at the time of admission and discharge. Each line of the CHI register had to be labelled in order to account for the multiple address combinations which may be associated with an individual and a place of residence and also to ensure the variable took account of changing residency over time, incorporating the dates from the CHI record. A pragmatic approach was taken in this work as there was no reference standard or existing methodology to adopt. Manual researcher classification of all records is laborious and this project provided an opportunity to test and develop methodologies applicable to other research.

#### 8.3.3.3 Methods to assist in classifying addresses from the CHI register

Several methods were tested to classify addresses:

**1. Postcode matching** – postcode matching was performed by computer, comparing postcodes in the CHI records with care home postcodes in the Care Inspectorate list, removing any spaces between characters, identifying a match if these were identical.

**2. Algorithm methods**– two algorithms (Metaphonics and SoundX) were combined by HIC to match care home addresses from CHI records to the Care Inspectorate list. Metaphonics is a computational technique to convert each word of a string variable (such as an address) into phonetics (metaphonic words), based on how they are pronounced in English (Beider and Morse, 2010). These can then be compared using SoundX, in which words are given a numerical value and compared with words which sound alike (Beider and Morse, 2010). A match score (%) is calculable for the original string variable and the address it has been matched to, based on how similar they are. Cut-offs were selected by the team at HIC following review of the data. HIC decided a match occurred when the postcode matches a care home postcode and the algorithm score is >85%, or if the algorithm score is >95%.

**3. Postcode Address File®** (PAF) technology from the Post Office – was used to correct errors in addresses by converting address details into barcodes of letters and numbers. This was used to match addresses from CHI records to the Care Inspectorate list.

**4. Care home keywords** – a word frequency analysis was performed using CHI records which had matched as care home addresses and been agreed as care home addresses by BG & JKB (**Table 8.2a**). This list included mis-spellings where address details were incorrect in CHI records. However, some of these terms were specific to Fife care homes and may not be generalisable, so a second list of generic keywords were agreed within the research team (**Table 8.2b**).

**Table 8.2: Keywords used to identify care home addresses**

| a) Keywords from word frequency analysis of agreed care home addresses | | |
|---|---|---|
| Abbotsford Care | Craigmount Nursing | Lodge Nursing |
| Abbotsford Nursing | Ct Nursing | Marchmount Residential |
| Balfarg Residential | Henderson House | Methven House |
| Balhousie | Hill Nursing | Nurs Home |
| Bay Care | Hme | Nursing |
| Bay Nursing | Home | Nursing Hom |
| Beach Nursing | Home 31A | Nursing Home |
| Beeches Care | Home 91C | Quarriers Homes |
| Beeches Ladysmill | Home Bennochy | R Home |
| Beeches Nursing | Home Carswell | Res |
| Benore Care | Home Kilmichael Home Main | Res Home |
| C Home | Home Sea | Residentia |
| Camilla Nursing | Home Star | Residential |
| Care | Home Walker | Residential Hom |
| Care Centre | Home Walkerton | Residential Home |
| Care Home | Homes Bridg | Residentiel |
| Care Nursing | House Blair | Servite |
| Carehome | House Nursing | Servite Court |
| Centre | Hse Care | Strathview Care |
| Court Care | Level Nursing | View Nursing |
| Court Nursing | Lodge Care | |
| **b) Generic keywords to identify care homes** | | |
| Nur* Hom* | | |
| Care Home | | |
| Care HM | | |
| res* hom* | | |
| Nur* HM | | |
| Res* HM | | |
| NR Hom* | | |
| Care Centre | | |

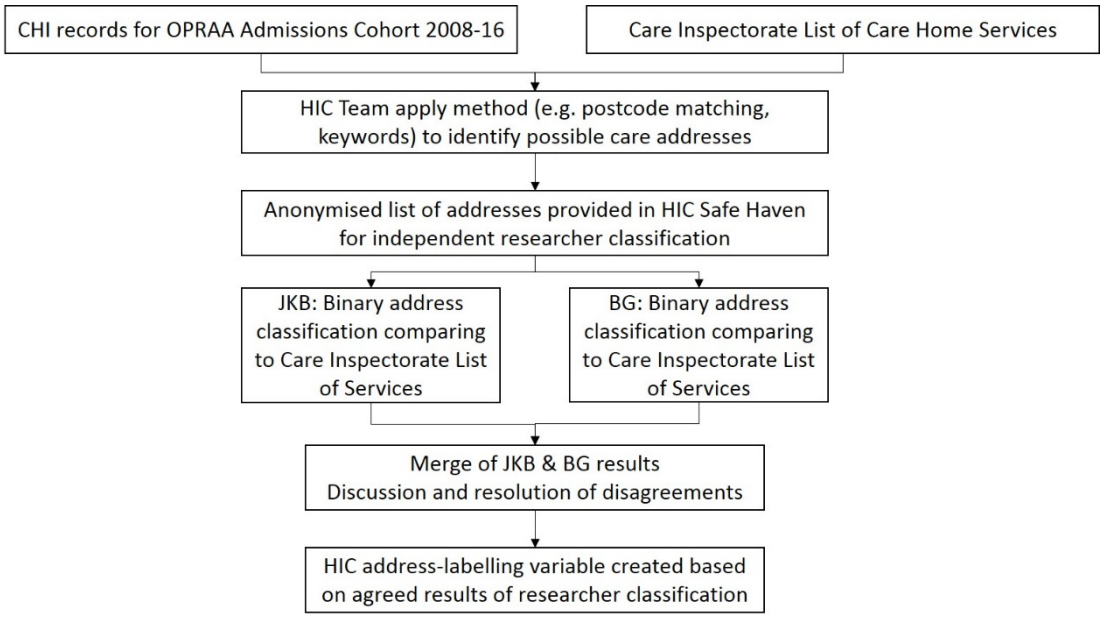
#### 8.3.3.4 Classification of addresses

HIC analysts used the methods described above to reduce the results which required independent classification. They generated lists of addresses which were considered to be possible 'care home' addresses and removed all other CHI record variables. The lists of addresses were independently classified by JKB and BG. Classification consisted of comparing the addresses with the Care Inspectorate list of services to determine if the address was a 'care home' or 'not a care home'. Looking at addresses which had been identified as possible care homes helped to appreciate the strengths and limitations of each approach. Descriptive analysis of the issues encountered by use of these methods is provided in Section 8.4.1.

At each stage, addresses which JKB and BG classified as 'care home' or 'not a care home' were stored by HIC to populate the HIC address-labelling variable classifying all available addresses in the CHI register. The process of classifying records is summarised in **Figure 8.1**. Addresses which had been identified as 'care home' were not re-evaluated in the subsequent methods.

Although the focus of the project was allocating care home addresses, it was important to ensure that those labelled as 'not care home' addresses were also correct. From the pool of addresses which had been labelled as 'not care home' addresses, two random samples each of 1,000 addresses were obtained to estimate the error rate.

**Figure 8.1: Pictorial summary of procedure for classifying records to create HIC address-labelling variable**




*Footnotes: BG – Professor Bruce Guthrie; CHI – Community Health Index; HIC – Health Informatics Centre; JKB – Dr Jenni Kirsty Burton*

#### 8.3.3.5 Rules for classifying addresses

Rules were developed during the classification process to standardise the approach taken and deal with unclear results.

Some care facilities have mixed provision, e.g. a care home within a sheltered housing complex. If the CHI address specified the care home name, or other acknowledgement of residency in the care home, this was included as 'a care home'. When such detail was lacking, however, it was assumed to be part of the sheltered housing provision and assigned as 'not a care home'. Where discrepancies arose in classification between assessors, additional information was sought from care facility websites and Google Maps®. All disagreements were resolved by discussion between assessors.

Where address data contained a street name without a number or an institution name, this was assigned as 'not being a care home' due to the ambiguity in the address. Similarly, if a care home address was registered with an institution name and a street number and neither was included in the CHI address, this was also assigned as 'not being a care home'.

### *8.3.4 Checking of the HIC address-labelling variable (Aim two)*

It was recognised that the SMR01 data may not be correct, and that the HIC address-labelling variable may contain errors. In the absence of a true reference standard, it was agreed that any disagreements between SMR01 and the HIC address-labelling variable would be checked. Disagreements were defined as cases where the HIC address-labelling variable stated the address was a care home, but SMR01 stated the individual was admitted from a private address and also where SMR01 stated the individual was admitted/discharged to a care home, but the HIC address-labelling variable disagreed. The project statistician provided HIC with a list of the case numbers for those where disagreement was found. HIC analysts extracted the addresses from the CHI records which corresponded to the dates of admission and discharge. JKB and BG evaluated the addresses independently, with reference to the Care Inspectorate list, to determine if they were care home addresses or not. These results were sent to HIC, which updated the HIC address-labelling variable, correcting any errors identified. This corrected file was used in the analysis described in Section 8.3.5.

### *8.3.5 Accuracy of SMR01 and the CHI Care Home Flag (Aims three & four)*

The usual approach available to researchers to identify care home residents uses the fields or flags within routine health data sources. These include:

1. SMR01 'admitted/transferred from' and 'discharged/transferred to' fields
2. CHI Care Home Flag

Using the data available from the OPRAA project it was possible to evaluate the performance of the SMR01 variables against the HIC address-labelling variable derived using underlying address data in a secure environment, as described above. The completeness and accuracy, defined as the sensitivity, specificity, positive and negative predictive values of SMR01 'admitted/transferred from' and 'discharged/transferred to' data in determining care home residency were evaluated using a specially-defined two-year cohort. This approach allowed for the creation of a two-by-two table (**Table 8.3**) for residency.

**Table 8.3: Sample two-by-two table**

| | | Reference standard | |
|---|---|---|---|
| | | **Care home address** | **Not care home address** |
| **Comparison method (SMR01, CHI CH flag)** | **Care home address** | True Positives | False negatives |
| | **Not care home address** | False positives | True negatives |

As the CHI register is updated monthly, it was decided that while residency at admission would be based on the date of admission alone, residency at discharge would allow a period of 30 days for any changes in the CHI record to be reflected in the analysis.

The CHI Care Home Flag became available to HIC in August 2015, outwith the OPRAA project period, so a cross-sectional review was not possible using the OPRAA data. The flag is attached to the CHI record, so access to a different data set was required to evaluate the performance of the CHI Care Home Flag. Additional data were requested by BG to evaluate the residency of adults aged ≥65 years living in the NHS Fife and NHS Tayside regions on 1st April 2017. A random sample of a total of 10,000 addresses was obtained, half from each Health Board area. Residency could be determined on this specific date and compared with the most recent update of the Care Inspectorate list of services from 31st March 2017. The n=10,000 sample was independently classified by JKB and BG to classify addresses as 'care home' or 'not care home' addresses, to form a reference standard. The performance of the CHI Care Home Flag was evaluated against this reference standard to create a two-by-two table, allowing calculation of the accuracy of the flag.

A summary of all the datasets used and analyses conducted is provided in **Figure 8.2**.

**Figure 8.2: Summary of the analysis performed to achieve the four aims**

**AIM ONE: to evaluate methods to identify care home residents in routinely-collected health data, to develop an address-labelling variable to indicate if the address is a care home or not**

A pragmatic approach was taken as there was no REFERENCE STANDARD to use

**DATA SOURCE & SAMPLE**: N=115,124 CHI records
All CHI records for those in the OPRAA Admissions Cohort from 2008-16

**METHODS**: Postcode matching, algorithms, Postcode Address File, care home keywords. Used to identify addresses for researcher classification of 'care home' or 'not care home'. Once these steps were complete the HIC address-labelling variable was linked into the dataset for analysis.

**AIM TWO: to apply the address labelling variable as a reference standard to the OPRAA incident cohort analysis and check its accuracy**

**DATA SOURCE**: OPRAA Incident Cohort

**SAMPLE**: N=6,724 incident admissions to the Acute Medical Unit of adults ≥65 years in NHS Fife January 2012 to December 2013

**EVALUATION**: HIC address labelling was compared to SMR01

Cases where these 'disagreed' were reviewed to determine which source was correct. Addresses were independently classified as 'care home' or 'not care home'. Any errors in the HIC address labelling variable were corrected before use in the next stage.

**AIM THREE: to determine the accuracy of the SMR01 admission and discharge coded variables**

**DATA SOURCE**: OPRAA Admissions Cohort

**SAMPLE**: N=18,767 emergency admissions to medicine of adults ≥65 years in NHS Fife

**INDEX TEST**: SMR01 admitted/transferred from and SMR01 discharged/transferred to

**REFERENCE STANDARD**: corrected HIC address labelling variable

**AIM FOUR: to evaluate the CHI Institution Flag performance**

**DATA SOURCE**: Master CHI Register

**SAMPLE**: N=5,000 records from NHS Tayside and N=5,000 records from NHS Fife

**INDEX TEST**: CHI Institution Flag indicating care home

**REFERENCE STANDARD**: manual classification of 10,000 addresses as 'care home' or 'not care home'

### *8.3.6 Approvals*

The data for this project were stored and managed by HIC which provided access to anonymised data held in a secure safe haven environment which did not permit data export. The Standard Operating Procedures used by HIC have been reviewed and approved by the NHS East of Scotland Research Ethics Committee. Permission for access to the data used in these studies was obtained from the NHS Fife and NHS Tayside Caldicott Guardians [IGTCAL4179 4/9/17].

### *8.3.7 Statistical analysis*

SAS Version 9.4 was used to define the cohort for analysis, to merge the HIC address-labelling variable with the SMR01 cohort data and to analyse admission and discharge residency, comparing SMR01 with the HIC address-labelling variable. Sensitivity, specificity, positive predictive value and negative predictive value were calculated after forming two-by-two tables. 95% confidence intervals were calculated using Vassar Stats Statistical Computation Clinical Research Calculators (Lowry, 2017).

## 8.4 RESULTS

### *8.4.1 Preparatory methods to create the HIC address-labelling variable (Aim one)*

A total of 36,890 patients were included in the OPRAA admissions cohort. These patients have a total of 115,124 CHI records, of which only 48,212 represent unique addresses and postcodes.

#### 8.4.1.1 Postcode matching

The 48,212 unique addresses and postcodes extracted from the CHI record were compared with the Care Inspectorate list to identify potential matches. 6,286 (13%) matched to a care home postcode. 1,200 (2.5%) had an invalid postcode so could not be classified using this method.

All 6,286 'matching' addresses were classified by JKB and BG independently to determine whether the address was a care home or not. There was agreement in 97% of cases:

- 5,180 (82%) – were judged to be care homes by both reviewers.
- 932 (15%) – were judged NOT to be care homes by both reviewers.
- 174 (3%) – reviewers did not agree on first assessment.

Among the 932 which were not considered to be care homes, a common issue was that the address in the CHI record was a residential address within the same postcode as a care home.

A meeting was held at HIC to discuss the 174 cases where JKB and BG disagreed. From these, 120 (69%) were not considered to be care homes and were mainly sheltered housing facilities or mixed care provision; 49 (28%) were considered to be care home addresses and five (3%) were considered unclear based on the data available. The unclear cases were categorised as 'not care home addresses' and these typically lacked a number or property name. This large review exercise and discussion allowed the agreement of the rules, described in Section 8.3.3.5, to classify future addresses. After completion of the manual review of cases (n=6,286) where the

postcode matched to a care home postcode, the matched address was considered to be a care home 83% of the time, with the remainder being incorrectly labelled.

No calculations could be made regarding the 40,726 addresses with a valid postcode which did not match on postcode-matching to a care home address. It would not be appropriate to construct a two-by-two table as this may include care home addresses.

#### 8.4.1.2 Algorithms

Looking at the results of algorithm-driven address matching enabled an appreciation of the non-standardised presentation of care home addresses in comparison with usual residential addresses – which typically appear as: house number/name, street, town/city and postcode. Care home addresses included additional details, such as resident room numbers or the building name within the care home. They often featured the care home provider organisation name, instead of the street number or name. The same postcode could match to more than one 'care home name' either due to the proximity of residence or change in care home provider resulting in a name change. No numerical data are presented as the algorithms were used by HIC to allocate addresses, without researcher classification.

#### 8.4.1.3 Postcode Address File®

Using PAF®, 161/1200 (13%) of addresses matched to care home addresses. However, independent classification by JKB and BG found that 43/161 (27% of those identified) were considered to be care home addresses and the remaining 116 were not care home addresses. Both reviewers were in complete agreement on these classifications.

#### 8.4.1.4 Use of keywords

Using keywords to allocate addresses which had not matched using postcodes, algorithms or PAF®, 530 addresses were identified as possible care home addresses. Independent classification by JKB and BG found 187 (35%) were considered to be care home addresses, but 328 (62%) were not. An additional 15 addresses were considered ambiguous, with disagreement between the reviewers. Following discussion all were labelled as 'not a care home'.

Looking at the possible matched addresses was illuminating to determine where the errors arose. The term 'centre' identified supported accommodation facilities and other non-care home organisations and featured in street names. 'Home' featured as a common term in residential addresses and other communal residential facilities. The most surprising error was the frequency of 'nursing' appearing before 'Queensferry' and other terms such as 'street', 'links' or 'road'. Eventually it was concluded that 'North' was frequently incorrectly entered as 'nursing' and the single error 'Nursing Queensferry' was found in 22% of these non-care home addresses.

The generic keywords matched a further 139 addresses as being possible care homes. Independent classification confirmed that 135 (97%) of these were care home addresses and

both reviewers were in complete agreement. The addresses which were not care home addresses were either nurses' residences or included the word 'home'.

#### 8.4.1.5 Error rate estimation

From the pool of >40,000 addresses not considered to be care home addresses, two random samples, each of n=1,000 were obtained. JKB and BG provided independent classification of both. This found eight (0.8%) addresses in the first sample and one (0.1%) address from the second sample which were care home addresses incorrectly labelled as not care home addresses. Having identified nine addresses out of 2,000 which were incorrectly classified, the error rate is 0.0045 (95%CI: 0.0024 – 0.0085) (Lowry, 2017).

After creation of the HIC address-labelling variable, from 48,212 unique addresses and postcodes 5% (2,230) were classified as care home addresses. These care home addresses appear in many different forms and are represented in a total of 20,872 CHI records. Extrapolating from the error rate data would mean that from the 45,982 'not care home' addresses we could expect to have missed 207 care home addresses (95%CI 110-390).

### *8.4.2 Checking the HIC address-labelling variable to form an OPRAA reference standard (Aim two)*

The HIC address-labelling variable was applied to the OPRAA incident cohort (n=6,724).

At the time of admission, a total of 239 (3.6%) cases 'disagreed' – in 73 (30.5%) the SMR01 record was 'care home' and the HIC address-labelling of the CHI record said 'not a care home' and in 166 (69.5%) the HIC address-labelling was 'care home' and the SMR01 was 'not care home'. After independent review by JKB & BG, the HIC address-labelling was correct in 69/73 (95%) and 148/166 (89%) cases.

At the time of discharge 300 (5.4% - excludes those who died as inpatients) cases 'disagreed' – in 117 (39%) the SMR01 record was 'care home' and the HIC address-labelling of the CHI record said 'not a care home' and in 183 (61%) the HIC address-labelling was 'care home' and the SMR01 was 'not care home'. After independent review by JKB & BG, the HIC address-labelling was correct in 111/117 (95%) and 168/183 (92%) cases.

Combining admission and discharge data, the HIC address-labelling was correct 92% of the time (496/539). Any cases where the HIC address-labelling variable was incorrect were corrected in the master file. This corrected file was considered the OPRAA project reference standard and used for the analysis described in Section 8.4.3.

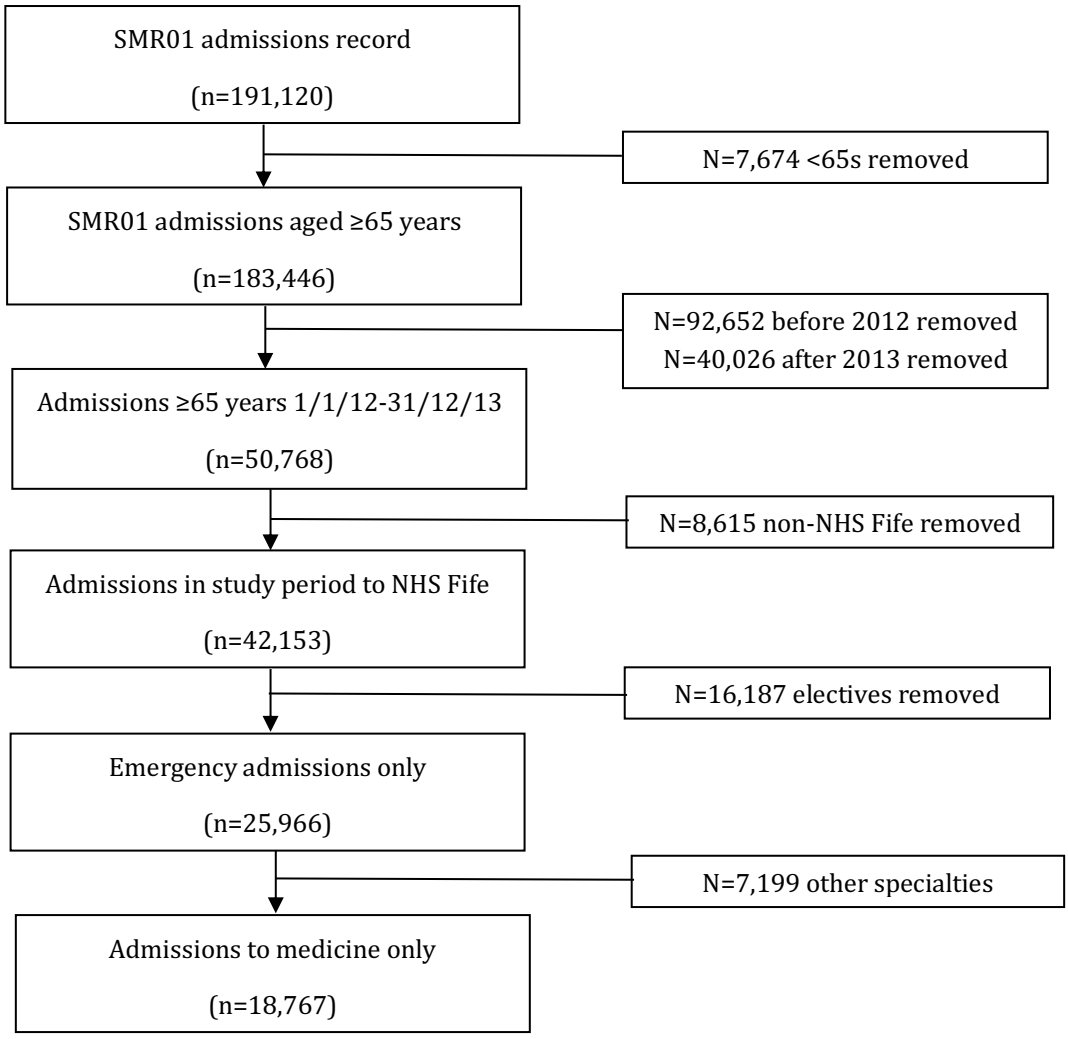
### *8.4.3 Accuracy of SMR01 coding in identifying care home residents (Aim three)*

#### 8.4.3.1 Cohort definition

The OPRAA admissions cohort data includes all SMR01 records for individuals aged ≥65 years admitted to AMU in NHS Fife at least once between January 2008 and January 2016

(n=191,120). To reduce this to those eligible for analysis, several steps were followed (**Figure 8.3**).

**Figure 8.3: Summarising OPRAA admissions cohort definition from original linked file**




In the period 1st January 2012 – 31st December 2013 there were 18,767 eligible admissions: 9,075 from 2012 and 9,692 from 2013. These included a total of 11,536 unique individuals.

The age of these admissions ranged from 65-105 years, median age 78 years [interquartile range 12]. Length of stay ranged from 1-863 days, median length of stay was six days [interquartile range 12].

#### 8.4.3.2 Admitted/transferred from

A description of the distribution of SMR01 data for where an individual was 'admitted or transferred from' is provided in **Table 8.4**.

**Table 8.4: SMR01 admitted/transferred from**

| Code | Number (%) |
|---|---|
| **Private residence** | |
| Living alone | 6822 (36.4) |
| Living with relatives, friends | 10437 (55.6) |
| Supported accommodation | 118 (0.6) |
| Other (temporary, type not known, other) | 31 (0.2) |
| Care home/institution (other type) | 1349 (7.2) |
| Transfer | 12 (0.1) |
| | Total = 18,767 |

Analysis includes a total of n=18,720 valid admissions which could be compared out of a possible 18,767 (99.7% completion). Cases which were coded as 'transfers' were excluded (38 cases, 0.2% of total) and individuals not normally resident in Fife or Tayside at the time of their admission (nine cases, 0.05% of total) could not be included in the analyses as their CHI records were not available to HIC.

There were 379 'disagreements' (2%), in 191 cases the SMR01 field stated the individual was admitted from a care home and the HIC address-labelling variable said they were not and 188 cases where the HIC address-labelling variable showed the individual was admitted from a care home, but the SMR01 record did not.

If the HIC address-labelling variable is assumed to be correct, the total number of admissions from a care home was 1346 (7%). A two-by-two table was created from the data (**Table 8.5**).

**Table 8.5: SMR01 *versus* HIC address-labelling in identifying admissions from care homes**

| | | Reference standard Corrected HIC address-labelling | | |
|---|---|---|---|---|
| | | **Care home address** | **Not care home address** | |
| **SMR01 Admitted/transferred from** | **Care home** | 1,158 | 191 | 1,349 |
| | **Not care home** | 188 | 17,185 | 17,373 |
| | | 1,346 | 17,376 | 18,722 |

Therefore, the sensitivity of the SMR01 admitted/transferred from variable for identifying care home residency on admission to hospital is 86.0% (95%CI 84.0-87.8%), specificity is 98.9% (95%CI 98.7-99.0%), positive predictive value is 85.8% (95%CI 83.8-87.6%) and negative predictive value is 98.9% (95%CI 98.7-99.0%). Sensitivity in this context denotes the proportion of all care homes correctly identified by the SMR01 variable and the positive

predictive value represents the likelihood that someone identified in SMR01 as being admitted from a care home, was admitted from a care home address.

#### 8.4.3.3 Discharged/transferred to

A description of the distribution of SMR01 data for where an individual was discharged or transferred to is provided in **Table 8.6**. Mortality data were calculated from the CHI record for the entire study cohort. These data did not always agree with the coding in the SMR01 record and where disagreement occurred, the CHI record was trusted as being correct with respect to mortality.

**Table 8.6: SMR01 discharged/transferred to**

| Code | Number of records N (%) | Corrected for mortality N (%) |
|---|---|---|
| Died as inpatient | 2,197 (11.7) | 2,258 (12.0) |
| **Private residence** | | 14,292 (76.2) |
| Living alone | 4,755 (25.3) | |
| Living with relatives, friends | 8,920 (47.5) | |
| Supported accommodation | 233 (1.2) | |
| Other (temporary, type not known, other) | 447 (2.4) | |
| Care home/institution (other type) | 1,662 (8.9) | 1,662 (8.9) |
| Transfer | 553 (2.9) | 555 (3.0) |
| **TOTAL** | **18,767** | **18,767** |

A total of 12% of the cohort died during their inpatient hospital stay. Analysis of discharge coding includes a total of n=15,948 valid discharges which could be compared out of a possible 16,509 (96.6% completion). Cases which were coded as 'transfers' were excluded (361 cases, 2.3% of total) and individuals not resident in Fife or Tayside at the time of their admission (five cases, 0.03% of total) could not be included in the analyses as their CHI records were not available to HIC.

There were 468 'disagreements' (3%). Of these, there were 258 cases where the SMR01 field stated the individual was discharged to a care home and the HIC address-labelling variable said they were not and 210 cases where the HIC address-labelling variable showed the individual was discharged to a care home, but the SMR01 record did not.

If the HIC address-labelling variable is assumed to be correct, the total number of discharges to a care home was 1,613 (10%). A two-by-two table was created from the data (**Table 8.7**).

**Table 8.7: SMR01 *versus* HIC address-labelling for identifying discharges to care homes**

| | | Reference standard Corrected HIC address-labelling | | |
|---|---|---|---|---|
| | | **Care home address** | **Not care home address** | |
| **SMR01 Discharged/transferred to** | **Care home** | 1,403 | 258 | 1,661 |
| | **Not care home** | 210 | 14,077 | 14,287 |
| **TOTAL** | | **1,613** | **14,335** | **15,948** |

Therefore, the sensitivity is 87.0% (95%CI 85.2-88.6%), specificity is 98.2% (95%CI 98.0-98.4%), positive predictive value is 84.5% (95%CI 82.6-86.1%) and negative predictive value is 98.5% (95%CI 98.3-98.7%) for the SMR01 discharged/transferred to variable in identifying care home residency at discharge. Sensitivity in this context denotes the proportion of all care homes correctly identified by the SMR01 discharged/transferred to variable and the positive predictive value represents the likelihood that someone identified in SMR01 as being discharged to care home, was actually discharged to a care home address.

### *8.4.4 Accuracy of the CHI Care Home Flag in identifying care home residents (Aim four)*

This analysis is based on a random sample of 10,000 CHI records from the population of adults aged ≥ 65 years who were resident in NHS Fife and NHS Tayside. The distribution of responses included in the CHI Institution Flag is reported in **Table 8.8**.

**Table 8.8: CHI Institution Flag results**

| **Institution Code** | **NHS Fife** | **NHS Tayside** |
|---|---|---|
| | **Number of cases (%)** | **Number of cases (%)** |
| **Care home**<br>93 – residential home<br>98 – nursing home | <br>80 (1.6)<br>247 (4.9) | <br>138 (2.8)<br>256 (5.1) |
| Other institution | 273 (5.5) | 31 (0.6) |
| No flag assigned | 4400 (88.0) | 4575 (91.5) |
| **TOTAL** | **5000** | **5000** |

In total, 987 care home addresses were identified after JKB and BG had performed independent classification of the address data. The prevalence of care home addresses was 9.9%. The performance of the CHI institution flag is reported in **Tables 8.9 & 8.10**.

**Table 8.9: CHI Care Home Flag NHS Fife *versus* Reference Standard Address Classification**

| | | Reference Standard Manual address classification | | |
|---|---|---|---|---|
| | | **Care home address** | **Not care home address** | |
| **CHI Care Home Flag** | **Care home address** | 326 | 1 | **327** |
| | **Not care home address** | 230 | 4443 | **4673** |
| **TOTAL** | | **556** | **4444** | **5000** |

**Table 8.10: CHI Care Home Flag NHS Tayside *versus* Reference Standard Address Classification**

| | | Reference Standard Manual address classification | | |
|---|---|---|---|---|
| | | **Care home address** | **Not care home address** | |
| **CHI Care Home Flag** | **Care home address** | 385 | 9 | **394** |
| | **Not care home address** | 46 | 4560 | **4606** |
| **TOTAL** | | **431** | **4569** | **5000** |

In NHS Fife, the sensitivity is 58.6% (95%CI 54.5-62.7%), specificity is 99.9% (95%CI 99.8-99.9%), positive predictive value is 99.7% (95%CI 98.0-99.9%) and negative predictive value is 95.1% (95%CI 94.4-95.7%) for the CHI Care Home Flag in identifying care home residency. In NHS Tayside, the sensitivity is 89.3% (95%CI 85.9-92.0%), specificity is 99.8% (95%CI 99.6-99.9%), positive predictive value is 97.7% (95%CI 95.6-98.9%) and negative predictive value is 99.0% (95%CI 98.7-99.3%) for the CHI Care Home Flag for identifying care home residency.

Sensitivity in this context denotes the proportion of all care homes correctly identified by the CHI Care Home Flag and the positive predictive value represents the likelihood that someone identified with the CHI Care Home Flag as living in a care home, lives at a care home address.

## 8.5 DISCUSSION

### *8.5.1 Key findings*

Reliably identifying care home residents in routine health data sounds simple and something which clinicians and researchers would assume to be possible. However, as this Chapter has identified this has proved to be a complex task.

#### 8.5.1.1 Creation and checking of the HIC address-labelling variable to identify care home residents in routinely-collected health data (Aims one and two)

The preparatory work to determine the HIC address-labelling variable provides detail around the key issues:

1. Postcodes alone are unreliable because they match multiple residences, including those living at private addresses as care home residents.
2. Care home addresses are often not provided in a standard format, limiting the use of algorithms and existing software to extract numbers and phrases and match to agreed address data.
3. Certain keywords can be helpful to identify care home addresses. However, terms such as 'centre' are not specific enough to identify care homes, and typographical errors (e.g. nursing for North) can be unpredictable, but recurrent.

These iterative steps were necessary to create the HIC address-labelling variable, but in spite of independent classification of >9,000 addresses, additional checking was needed before finalising the care home residency variable for the OPRAA project. This is largely due to the multiplicity of data available relating to single individuals, as the denominator was number of CHI records, not people.

#### 8.5.1.2 Accuracy of SMR01 coding in identifying care home residents (Aim three)

The SMR01 performance in Fife was better than had been anticipated, with sensitivity at admission of 86% and at discharge of 87% and positive predictive value of 86% on admission and 84% at discharge. The sensitivity in this context relates to how well SMR01 identifies care home residents while the positive predictive value is the proportion of those whom SMR01 identifies as a care home resident actually are care home residents (Bossuyt *et al*., 2013).

#### 8.5.1.3 Accuracy of the CHI Care Home Flag in identifying care home residents (Aim four)

The performance of the CHI Institution Flag differed in the two Health Board areas. In NHS Fife, the flag had a much lower sensitivity at 58%, but a positive predictive value of 99%. Thus, only 58% of care home residents are flagged as such, however 99% of those in whom the flag denotes care home residency are actually care home residents. In NHS Tayside the flag had a better sensitivity of 89% and retains the excellent positive predictive value of 98%. This indicates that when the flag is present it is likely to be correct, however the completeness varies between areas. Such information is valuable to researchers using routine data from NHS Fife and NHS Tayside to identify care home residents who will probably only have access to these

flags to define residency status. The variation suggests, however, that these figures may not be generalisable to other Health Board areas and this warrants further investigation.

### *8.5.2 Strengths*

The findings presented in this Chapter result from the rare opportunity to compare the system-level coding with underlying source data and to explore the underlying 'errors' in classification. This required a team approach in which address data were made available to the researchers in a secure environment and the results of independent classification were reunited with clinical records by appropriate data science personnel. Forming a reference standard address allocation required a robust classification procedure carried out by two independent assessors providing clinical assessment and sense-checking of the results of computerised and automated processes. The repeated pairing of JKB and BG helped ensure consistency in approach and allowed for discussion of equivocal cases. The work has a practical application and arose from a research need to classify residency in order to analyse outcomes following hospitalisation.

### *8.5.3 Limitations*

There are important limitations in the work presented. The HIC address-labelling variable was checked for the OPRAA incident cohort data, but was not repeated for the OPRAA admissions cohort analysis presented here, due to time and resource restrictions. The rationale for using a different cohort to perform these analyses was to provide training in the use of SAS and syntax for data manipulation. That said, the checks performed for the project cohort found the HIC address-labelling variable was correct in 92% of cases and any errors identified were incorporated into the reference standard used in this analysis.

In total, 0.3% of admission records and 3.4% of discharge records could not be included in the analysis. The commonest reason was that these were coded as 'transfer' so there was ambiguity about where the individual came from and was discharged to. A pragmatic decision was made to trust the linkage of these admissions as discrete admissions. This analysis is predicated on accepting that not all admission and discharge coding is accurate, reflected in even the incorrect recording of mortality in SMR01 *versus* CHI. The linkage for the project was done with sight of admission and discharge dates and thus was considered a trusted source. A much smaller group of admission records was excluded as the individual was not normally resident in Fife on admission, so had to be excluded due to lack of address data available to HIC. That the data only reflect practice in one Health Board area is a significant limitation in terms of generalisability, as the accuracy of coding is known to vary between hospitals (Information Services Division Scotland and NHS National Services Scotland, 2012) and, apart from the differences noted between Fife and Tayside, this could not be explored further in this analysis. Variation in the accuracy of coding is an important consideration when performing Scotland-wide analyses or for researchers using data from other Health Board areas.

The methods tested when developing the HIC address-labelling variable could not be described in terms of their sensitivity, specificity and predictive values as only addresses which matched

as care homes were examined. These steps were to generate knowledge about the advantages and limitations of each method and were performed on different sub-samples of the cohort data.

Finally, the frequency of updates of the CHI record necessitated allowing a 30-day period after discharge to evaluate the outcome of 'discharge to care home'. This may misclassify those admitted to a care home from their own home within 30 days of hospital discharge as having been discharged directly to a care home. Interestingly, the sensitivity results are comparable between admission and discharge, so there is no convincing evidence of this being attributable for SMR01 performance.

### *8.5.4 Implications*

To improve the identification of care home residency using routine data, multiple approaches are likely to be required, including local quality improvement work to target clinical coding errors and residency assignment with review of the heterogeneous clinical systems to ensure this process is as simple as possible. IT infrastructure, in which lookups populate more standardised address data than may be provided by individuals, would help standardise the data generated on local clinical systems. The differences in the CHI Care Home Flag performance between areas would support further evaluation across the other Scottish Health Boards.

One challenge is that 'care home residency' can be considered a low-prevalence condition. Even among the population aged ≥65 years included in these analyses, they represented <10% of the samples. Therefore, the two-by-two table is significantly weighted as most individuals are 'not care home residents'. It could be argued that misclassification is not important. Its importance, however, will depend on the research question and primary outcome of interest, particularly if an intervention is being evaluated.

The question of interest will determine which method of identifying care homes is most appropriate. Use of postcode matching alone correctly identified 83% of care home addresses, but would have incorrectly resulted in 17% of non-care home addresses being included as care homes. If the CHI Institution Flag were used in Fife, 42% of care home addresses would not be identified, while in Tayside 11% of care home addresses would not be identified by this method. In the OPRAA project, exclusion of existing care home residents was necessary to define the primary outcome of living at home 30 days after discharge. From the 6,724 individuals included in this analysis, 500 (7.4%) were considered care home residents at the time of admission using the OPRAA reference standard. Reliance on hospital (SMR01) coding alone would have missed 148 care home residents (30%) and misclassified a further 69 who were living at home as care home residents (1%). Here the differential effect of misclassification is demonstrated depending on whether the care home residents are the focus of interest, or a subgroup within a much larger population. Alternatively, had the study aimed to identify new institutionalisation as the primary outcome, missing such a large group of existing care home residents would have been problematic. Researchers using routine linked data must be mindful that it will contain errors, but opportunities should be sought to describe and calculate these where practicable, in collaboration with data controllers to manage and maintain the separation of identifiable and de-identified data.

This work was made possible as part of a larger project to develop more automated approaches to identify care home addresses. I have been involved in assessing the performance of five methods using data from both Fife and Tayside and have prepared and submitted the manuscript for publication.

## 8.6 CONCLUSIONS

This Chapter has identified why identifying care home residents in routine health data poses challenges to researchers. Using NHS data, it has been possible to assess the accuracy of SMR01 coding and the CHI Care Home Flag formally. Improving the quality and accuracy of national data requires the collaborative approach described in this Chapter, driven by researchers, quality improvement experts and clinicians motivated to use routinely-collected data.

# CHAPTER NINE
# Using the Scottish Care Home Census to explore new care home admission following hospitalisation

## 9.1 BACKGROUND

Chapter Seven provided an introduction to the concepts of linking health and social care data and introduced the Scottish Care Home Census (SCHC) as a potentially valuable data source. In Chapter Eight the challenges of identifying care home residency within health data sources were examined and analysed using data from NHS Fife and Tayside. In this chapter, unlinked SCHC data will be presented, with descriptive analysis provided of care home admissions over a three-year period, including description of regional variations. Thereafter, the methodology and progress towards linking the SCHC with other data sources will be described.

## 9.2 THE SCOTTISH CARE HOME CENSUS

### 9.2.1 What is the Scottish Care Home Census?

All care home services in Scotland are registered with the national regulator, the Care Inspectorate. The Scottish Care Home Census (SCHC) is an annual collection of care home service data. All homes are invited to submit data, which are then collated by the Information Services Division (ISD) and held by the Scottish Government Health and Social Care Analysis Division. Although described as a census, the data collection aims to record all activity over the previous year (1st April – 31st March), including all admissions, deaths and discharges, not just the status of individuals at the year-end (Information Services Division Scotland, 2016). Census submissions are completed by the care home staff, with additional information from the Regulator. The data have been collected since 2003 and electronic methods have been used since 2010 (Information Services Division Scotland, 2016). A summary of the results is published annually in the autumn and includes data tables which are available for download to explore variation by Local Authority area, age group and care home type (Information Services Division Scotland and NHS National Services Scotland, 2016a).

One other research group has used the data to date, linking two clinical trial cohorts to the census to ascertain care home admission as an outcome measure (Quinn *et al.*, 2017). Otherwise, use of the data has been limited to informing internal policy and monitoring trends (Information Services Division Scotland, 2012).

### 9.2.2 What data are recorded?

The census is split into two parts, the first requests aggregate data about the care home and the second collects individual data about the residents. Admissions are categorised into those for

short-stay, respite or long-stay. Only those classified as long-stay residents are included in the individual resident data collection. Long-stay residents are defined as:

> *"… residents whose intention at time of admission to a care home was to stay as a permanent resident, regardless of how long they actually stayed. Residents whose intention was only to stay for a short time (less than six weeks) but were resident for more than six weeks, are counted as long stay residents" (Information Services Division Scotland and NHS National Services Scotland, 2016a).*

The full census submission from the care homes contains identifiable information including the care home name and address. These are converted into a unique care home identifier variable, allowing removal of sensitive information, but retaining the ability to identify discrete care homes in different census years.

#### 9.2.2.1 Aggregate care home data

The aggregate data are entered by the individual care homes and the Care Inspectorate. The care homes are asked to supply information on their current address and nominated contact details, information on weekly charges and numbers of residents, admissions, discharges and deaths (Scottish Government, 2015b). The Care Inspectorate supplies additional information based on registration and service information completed in the annual return care homes submit to it (Care Inspectorate, 2015). This includes the main provision the care home accommodates, in addition to other 'client-need' categories which are the other client groups the care home can accommodate. Seventeen discrete client need categories are available, ranging from common categories such as older people, dementia, palliative & end-of-life care, but also include the more sensitive categories of: blood borne viruses, mothers & children and autistic spectrum disorders.

#### 9.2.2.2 Individual long-stay resident data

The care homes are also asked to supply information for each of their long-stay residents. This includes their CHI number, gender, name, date of birth, ethnicity, funding status, resident characteristics and information about their admission and, if applicable, discharge (Scottish Government, 2015b). Not all care homes have long-stay residents and not all care homes submit individual data, even if they supply aggregate information. The decision to submit resident data is at the discretion of the individual care homes, thus introducing a potential source of bias.

### 9.2.3 How complete is the Scottish Care Home Census?

A key consideration in using routinely-collected data is to explore their completeness. This helps to describe the confidence with which conclusions can be drawn, understand the potential biases and identify areas for targeting initiatives to improve data quality. The SCHC publications include estimates of completeness based on the returns received, but these primarily relate to return of aggregate information and are not consistently reported across the years of interest.

Although the SCHC data have been collected for more than a decade, the lack of use of the data for research means the SCHC can be considered a novel dataset. It is likely to be of considerable

interest for clinical research to help in shaping health and social care policy. Access was therefore granted to analyse the SCHC data as part of a Knowledge Exchange placement within the Health and Social Care Analysis Team in the Scottish Government to explore the data and document key aspects to support future research uses. Headline results from this work help contextualise the analyses presented later and thus a summary is presented below.

**Table 9.1** reports the completeness of aggregate data returns, presented by LA area, based on the total number of care homes open on the 31st March (i.e. end of census year). The number of open homes each year is falling. Census completion varies, 73.9-80.6% of all open homes per year. Completion is not evenly distributed, however, as between 56.0 and 100% of care homes in each LA area submit data.

Not all care homes have long-stay residents and neither will they necessarily have admissions each year. **Table 9.2** reports the number of care homes returning individual long-stay resident data, with the denominator here being the homes which reported they had one or more long-stay admission in the census year. Overall individual resident data submission ranges from 68.2 to 75.1% by census year of homes which reported having long-stay admissions. Completion varies among LAs, with 46.2-100% of homes in each area having admissions submitting data.

**Table 9.1: Completeness of Scottish Care Home Census Aggregate Data by Local Authority Area from 2013-2016 at 31st March**

| Local Authority | 2013/14 | | | 2014/15 | | | 2015/16 | | |
|---|---|---|---|---|---|---|---|---|---|
| | Nº of Open Care Homes | Nº of homes returning data | Completeness % | Nº of Open Care Homes | Nº of homes returning data | Completeness % | Nº of Open Care Homes | Nº of homes returning data | Completeness % |
| Aberdeen City | 69 | 55 | 79.7 | 64 | 50 | 78.1 | 64 | 47 | 73.4 |
| Aberdeenshire | 81 | 62 | 76.5 | 81 | 60 | 74.1 | 74 | 62 | 83.8 |
| Angus | 32 | 26 | 81.3 | 32 | 23 | 71.9 | 31 | 24 | 77.4 |
| Argyll & Bute | 25 | 14 | 56.0 | 24 | 15 | 62.5 | 24 | 18 | 75.0 |
| Clackmannanshire | 11 | 10 | 90.9 | 11 | 9 | 81.8 | 11 | 10 | 90.9 |
| Dumfries & Galloway | 41 | 31 | 75.6 | 38 | 27 | 71.1 | 37 | 32 | 86.5 |
| Dundee City | 34 | 27 | 79.4 | 33 | 23 | 69.7 | 33 | 26 | 78.8 |
| East Ayrshire | 28 | 22 | 78.6 | 27 | 22 | 81.5 | 26 | 22 | 84.6 |
| East Dunbartonshire | 18 | 13 | 72.2 | 18 | 13 | 72.2 | 18 | 14 | 77.8 |
| East Lothian | 20 | 12 | 60.0 | 19 | 13 | 68.4 | 19 | 15 | 78.9 |
| East Renfrewshire | 14 | 9 | 64.3 | 15 | 9 | 60.0 | 16 | 12 | 75.0 |
| Edinburgh City | 93 | 59 | 63.4 | 90 | 68 | 75.6 | 82 | 67 | 81.7 |
| Eilean Siar *(Outer Hebrides)* | 11 | 8 | 72.7 | 11 | 10 | 90.9 | 11 | 10 | 90.9 |
| Falkirk | 36 | 26 | 72.2 | 35 | 27 | 77.1 | 34 | 30 | 88.2 |
| Fife | 86 | 69 | 80.2 | 85 | 63 | 74.1 | 86 | 65 | 75.6 |
| Glasgow City | 133 | 104 | 78.2 | 129 | 98 | 76.0 | 120 | 92 | 76.7 |
| Highland | 81 | 64 | 79.0 | 74 | 54 | 73.0 | 73 | 65 | 89.0 |
| Inverclyde | 27 | 25 | 92.6 | 26 | 23 | 88.5 | 26 | 20 | 76.9 |

*Table 9.1 continued overleaf*

***Table 9.1 continued***

| Local Authority | 2013/14 | | | 2014/15 | | | 2015/16 | | |
|---|---|---|---|---|---|---|---|---|---|
| | Nº of Open Care Homes | Nº of CHs returning data | Completeness % | Nº of Open Care Homes | Nº of CHs returning data* | Completeness % | Nº of Open Care Homes | Nº of CHs returning data* | Completeness % |
| Midlothian | 19 | 11 | 57.9 | 18 | 11 | 61.1 | 16 | 12 | 75.0 |
| Moray | 22 | 19 | 86.4 | 22 | 19 | 86.4 | 22 | 21 | 95.5 |
| North Ayrshire | 32 | 22 | 68.8 | 29 | 19 | 65.5 | 29 | 21 | 72.4 |
| North Lanarkshire | 38 | 27 | 71.1 | 38 | 29 | 76.3 | 38 | 31 | 81.6 |
| Orkney Islands | 10 | 8 | 80.0 | 9 | 8 | 88.9 | 9 | 7 | 77.8 |
| Perth & Kinross | 51 | 33 | 64.7 | 50 | 31 | 62.0 | 49 | 38 | 77.6 |
| Renfrewshire | 27 | 20 | 74.1 | 29 | 24 | 82.8 | 25 | 23 | 92.0 |
| Scottish Borders | 28 | 20 | 71.4 | 28 | 18 | 64.3 | 24 | 19 | 79.2 |
| Shetland Islands | 12 | 10 | 83.3 | 10 | 9 | 90.0 | 10 | 10 | 100 |
| South Ayrshire | 30 | 19 | 63.3 | 31 | 25 | 80.6 | 31 | 28 | 90.3 |
| South Lanarkshire | 66 | 46 | 69.7 | 67 | 46 | 68.7 | 64 | 50 | 78.1 |
| Stirling | 26 | 19 | 73.1 | 25 | 15 | 60.0 | 24 | 18 | 75.0 |
| West Dunbartonshire | 13 | 10 | 76.9 | 13 | 12 | 92.3 | 14 | 8 | 57.1 |
| West Lothian | 35 | 23 | 65.7 | 35 | 28 | 80.0 | 35 | 30 | 85.7 |
| SCOTLAND | 1249 | 923 | 73.9 | 1216 | 901 | 74.1 | 1175 | 947 | 80.6 |

*Footnotes: Data are presented based on homes which finished and submitted the census*

*All percentages rounded to one decimal place*

**Table 9.2: Completeness of Scottish Care Home Census Individual Long-Stay Resident Data by Local Authority Area from 2013-2016, based on Care Homes which Reported Long-Stay Admissions**

| Local Authority | 2013/14 | | 2014/15 | | 2015/16 | |
|---|---|---|---|---|---|---|
| | Nº Care Homes with Long-Stay Resident Admissions | Nº (%) returning individual resident data | Nº Care Homes with Long-Stay Resident Admissions | Nº (%) returning individual resident data | Nº Care Homes with Long-Stay Resident Admissions | Nº (%) returning individual resident data |
| Aberdeen City | 46 | 33 (71.7) | 43 | 28 (65.1) | 41 | 27 (65.9) |
| Aberdeenshire | 56 | 44 (78.6) | 54 | 40 (74.1) | 55 | 43 (78.2) |
| Angus | 32 | 23 (71.9) | 32 | 20 (62.5) | 30 | 21 (70.0) |
| Argyll & Bute | 22 | 13 (59.1) | 21 | 14 (66.7) | 21 | 15 (71.4) |
| Clackmannanshire | 7 | 6 (85.7) | 7 | 6 (85.7) | 8 | 8 (100) |
| Dumfries & Galloway | 33 | 26 (78.8) | 33 | 22 (66.7) | 31 | 25 (80.6) |
| Dundee City | 29 | 19 (65.5) | 29 | 19 (65.5) | 29 | 22 (75.9) |
| East Ayrshire | 24 | 17 (70.8) | 23 | 18 (78.3) | 21 | 16 (76.2) |
| East Dunbartonshire | 15 | 12 (80.0) | 12 | 9 (75.0) | 13 | 10 (76.9) |
| East Lothian | 17 | 11 (64.7) | 17 | 11 (64.7) | 17 | 13 (76.5) |
| East Renfrewshire | 13 | 7 (53.8) | 15 | 8 (53.3) | 16 | 11 (68.8) |
| Edinburgh City | 65 | 43 (66.2) | 70 | 47 (67.1) | 68 | 51 (75.0) |
| Eilean Siar *(Outer Hebrides)* | 9 | 6 (66.7) | 9 | 7 (77.8) | 10 | 8 (80.0) |
| Falkirk | 28 | 21 (75.0) | 30 | 21 (70.0) | 28 | 21 (75.0) |
| Fife | 76 | 59 (77.6) | 77 | 52 (67.5) | 74 | 56 (75.7) |
| Glasgow City | 113 | 80 (70.8) | 111 | 73 (65.8) | 103 | 68 (66.0) |
| Highland | 66 | 50 (75.8) | 67 | 50 (74.6) | 68 | 51 (75.0) |
| Inverclyde | 20 | 15 (75.0) | 19 | 14 (73.7) | 20 | 13 (65.0) |

*Table 9.2 continued overleaf*

***Table 9.2 continued***

| Local Authority | 2013/14 | | 2014/15 | | 2015/16 | |
|---|---|---|---|---|---|---|
| | Nº Care Homes with Long-Stay Resident Admissions | Nº (%) returning individual resident data | Nº Care Homes with Long-Stay Resident Admissions | Nº (%) returning individual resident data | Nº Care Homes with Long-Stay Resident Admissions | Nº (%) returning individual resident data |
| Midlothian | 12 | 8 (66.7) | 12 | 9 (75.0) | 13 | 10 (76.9) |
| Moray | 15 | 12 (80.0) | 15 | 12 (80.0) | 15 | 15 (100) |
| North Ayrshire | 26 | 15 (57.7) | 24 | 14 (58.3) | 23 | 17 (73.9) |
| North Lanarkshire | 31 | 21 (67.7) | 31 | 21 (67.7) | 31 | 25 (80.6) |
| Orkney Islands | 4 | 4 (100) | 4 | 3 (75.0) | 4 | 3 (75.0) |
| Perth & Kinross | 47 | 22 (46.8) | 46 | 22 (47.8) | 46 | 26 (56.5) |
| Renfrewshire | 23 | 16 (69.6) | 25 | 22 (88.0) | 22 | 18 (81.8) |
| Scottish Borders | 22 | 14 (63.6) | 23 | 14 (60.9) | 22 | 18 (81.8) |
| Shetland Islands | 11 | 9 (81.8) | 9 | 7 (77.8) | 8 | 7 (87.5) |
| South Ayrshire | 26 | 16 (61.5) | 26 | 18 (69.2) | 27 | 25 (92.6) |
| South Lanarkshire | 58 | 35 (60.3) | 55 | 26 (47.3) | 53 | 43 (81.1) |
| Stirling | 19 | 9 (47.4) | 20 | 11 (55.0) | 19 | 13 (68.4) |
| West Dunbartonshire | 12 | 8 (66.7) | 12 | 11 (91.7) | 13 | 6 (46.2) |
| West Lothian | 22 | 14 (63.6) | 23 | 15 (65.2) | 20 | 16 (80.0) |
| MISSING | - | 2 | - | 4 | - | 7 |
| SCOTLAND | 999 | 690 (69.1) | 994 | 678 (68.2) | 969 | 728 (75.1) |

*Footnote: All percentages rounded to one decimal place*

## 9.3 ANALYSING CARE HOME ADMISSIONS

Having introduced the SCHC and contextualised the completeness of the data, the unlinked data were analysed to describe care home admissions.

### 9.3.1 Aim

The aim was to describe the characteristics of adults admitted to care homes in Scotland as long-stay residents over a three-year period, comparing those admitted from hospital with those admitted from home.

### 9.3.2 Methods

#### 9.3.2.1 Data sources

A standalone dataset was extracted by the Care Home Team within ISD and sent to eDRIS for researcher access *via* the National Data SafeHaven. This included all the aggregate data for the years of interest (2013/14, 2014/15 and 2015/16) and individual-level data on all admissions where the date of admission was recorded as being within those census years. The unique care home identifier, included in both the aggregate and individual datasets, enabled aggregate-level data about the care home to be analysed for individual long-stay residents. The analysis related to admissions rather than individuals because the data were unlinked, so there is no unique identifiable variable which could be checked across each of the census years.

#### 9.3.2.2 Included variables

The variables were divided into those obtained from the aggregate data, which are about the care home (**Table 9.3**) and those from the individual dataset, which are about the long-stay resident. Data were not requested on more sensitive categories of client needs, in order to reduce the privacy risk associated with these specialised care homes.

**Table 9.3: Aggregate care home variables** (Scottish Government, 2015b)

| Variable name | Definition |
|---|---|
| Care Home Subtype | Fixed category assigned by care inspectorate based on data provided by the care home at time of service registration |
| Service Type | Whether care home is run by private sector LA, voluntary/not for profit or by Health Board |
| LA Area of Care Home | Which LA the care home is located in, derived by ISD Care Homes Team based on postcode data |
| Health Board Area of Care Home | Which Health Board area care home is located in, derived by ISD Care Homes Team based on postcode data |
| Capacity | Number of beds in the care home for any type of admission |
| Main provision | Main client group for whom the care home can provide care, entered as part of the annual return to the Care Inspectorate |
| Client needs | Seventeen categories of 'client need' from which the care homes are asked to select all those relevant, entered as part of the annual return to the Care Inspectorate |

Variables from the individual resident data are summarised in **Table 9.4**, which includes the definitions provided to staff to facilitate census completion.

**Table 9.4: Individual long-stay resident variables** (Scottish Government, 2015b)

| Variable name | Definition |
|---|---|
| Date of birth | Month/Year |
| Sex | Female, Male, other |
| Ethnicity | White, other ethnic group, ethnicity not disclosed, ethnicity not known |
| Date of admission | Month/Year |
| Source of admission | Categories: another care home, hospital, other/not known, own home, and sheltered/supported accommodation |
| Date of discharge | Month/Year |
| Reason for discharge | Categories: another care home, death, hospital, other/not known, own home, and sheltered/supported accommodation |
| Mainly or wholly funded | Source of funding for placement providing majority or all of the costs |
| Free personal care and free nursing care | If individuals are privately funding their care, are they receiving the free personal care allowance and the free nursing care allowance |
| Local authority funds placement | If individuals are funded by their local authority, which funds their placement |
| Requires nursing care | Anyone who requires care which can only be given by a qualified nurse or under the supervision of a qualified nurse. |
| Dementia – medically diagnosed | Only include residents where Dementia has been diagnosed by a doctor. Dementia is defined as global deterioration of intellectual functioning. Normally a progressive condition resulting in cognitive impairment ranging from some memory loss and confusion to complete dependence on others for all aspects of personal care. **Please note: only one of the dementia boxes should be ticked for a particular resident.** |
| Dementia – not medically diagnosed | Include here people who staff believe to have dementia, but for whom no medical diagnosis has been made. Exclude confusion due to other causes e.g. medicines, severe depression. |
| Visual impairment | Anyone who is blind or partially sighted. If the sight problem can be resolved by wearing glasses or contact lenses then the person should not be listed as having a visual impairment. |

*Table 9.4 continued overleaf*

***Table 9.4 continued***

| | |
|---|---|
| Hearing impairment | Anyone with profound or partial deafness or other difficulties in hearing. If the hearing problem can be resolved by the use of a hearing aid then the person should not be listed as having a hearing impairment. |
| Acquired brain injury | People with an acquired brain injury usually have a complex mixture of physical, cognitive, emotional, and behavioural, disorders or difficulties. This may affect how the person perceives the world and their ability to remember, concentrate reason and judge. The person's emotional state may be disturbed; personality, behaviour, communication and relationships are also frequently altered. Mobility, sensation, vision, hearing and balance, smell and taste, respiration, heartbeat, bowel and bladder control may also be affected. There are many causes including damage to the brain through head injury, stroke, lack of oxygen, infection, or other causes. |
| Learning disability | A learning disability is a significant, lifelong condition which has three facets:<br>Significant impairment of intellectual functioning resulting in a reduced ability to understand new or complex information; and<br>Significant impairment of adaptive/social functioning resulting in a reduced ability to cope independently; and<br>Which started before adulthood (before the age of 18) with a lasting effect on the individual's development. |
| Other physical disability or chronic illness | Physical disabilities have many causes in chronic illness, accidents, and impaired function of the nervous system, which, in particular physical or social environments result in long term difficulties in mobility, hand function, personal care, other physical activities, communication, and participation.<br>***Include***: Severe epilepsy; limb loss; severe arthritis; diseases of the circulatory system (including heart disease); diseases of the central nervous system (e.g. strokes, multiple sclerosis, cerebral palsy, spina bifida and paraplegia).<br>**Please note: do not select this category if the following has already been selected: visual impairment, hearing impairment or acquired brain injury.** |
| Mental health problems | Mental health problems are characterised by one or more symptoms including: disturbance of mood (e.g. depression, anxiety), delusions, hallucinations, disorder of thought, sustained or repeated irrational behaviour. ***Include*:** People assessed as having mental health problems whether or not the symptoms are being controlled by medical treatment.<br>**Please note: do not select this category if the following has already been selected: dementia, alcohol related problems or drug related problems.** |

*Footnote: Wording of definitions is provided in guidance to care homes Scottish Government, 2015b*

#### 9.3.2.3 Data access and release of results

The data were accessed *via* the National Data SafeHaven, using remote access from within the University of Edinburgh. All analysis was performed using the remote access into the SafeHaven. All results for release (known as 'output') were subject to statistical disclosure control by the project research co-ordinator at eDRIS.

#### 9.3.2.4 Data cleaning and analysis

Within the project area in the SafeHaven, the data were imported in comma-separated value (csv) format into IBM SPSS Statistics Version 22.0. Original copies were unedited and saved separately. Syntax was created to correct inconsistencies in coding (e.g. spelling differences, spacing errors) and to format date variables to enable numerical calculations. Inconsistencies between census years (e.g. changes of categories, addition of new variables) were noted and

additional syntax written to incorporate these. A 'census year' variable was created to maintain a link to the original census year before merging the data into a single dataset.

The 'source of admission' variable was used to define the admissions included in the analysis. Admissions where the variable 'source of admission' was unknown were removed and transfers were separated from the main dataset. Source of admission was then dichotomised into admission from hospital or admission from home (including those in sheltered/supported accommodation and those admitted from their own home) and the analysis proceeded looking at the two groups.

SPSS syntax was created to carry out the descriptive analysis, recording numbers and the proportions within each group. An independent sample t-test was used to calculate difference in means. Maps were generated to display summary data on the proportion of care home admissions from hospital. These were generated using Tableau Software Version 10.4.1.

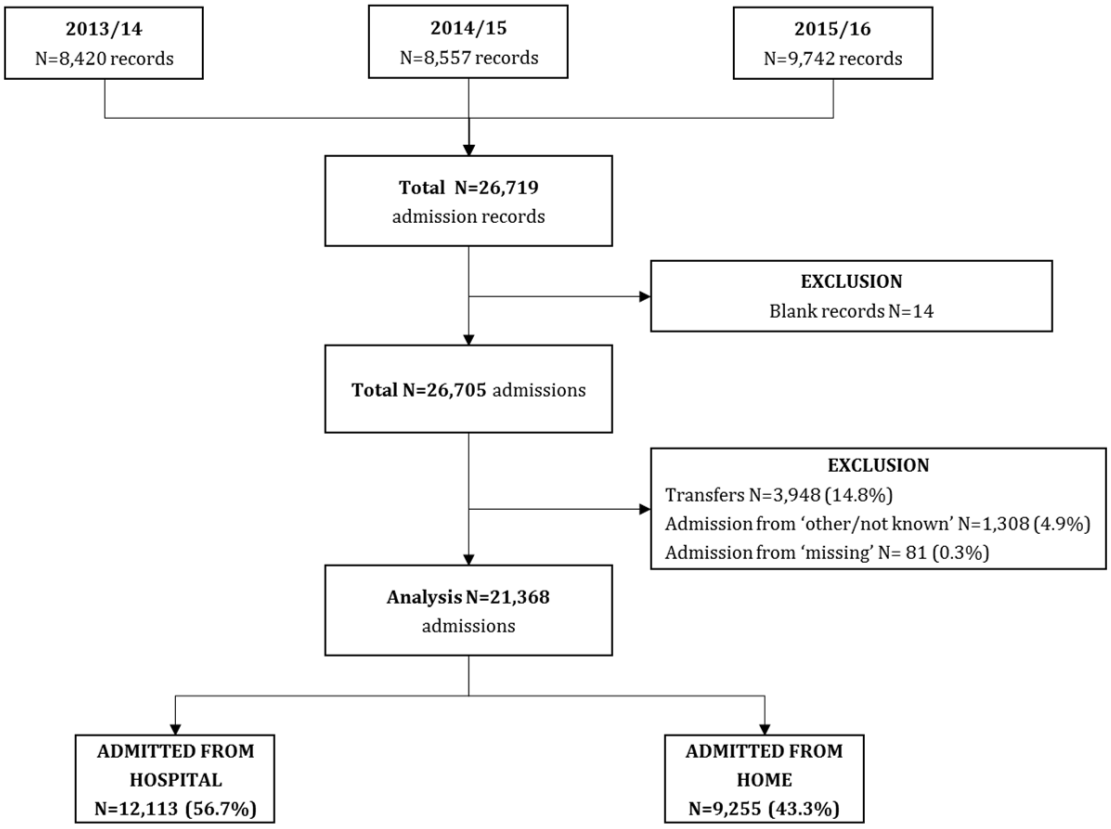
### 9.3.3 Results

#### 9.3.3.1 Data completeness and cohort definition

Individual resident admission data were available from 690 care homes in 2013/14, 678 in 2014/15 and 728 in 2015/16. This is estimated to be 70.8% complete (2096 homes returning resident admission data), based on the calculation of the number of care homes which reported any long-stay resident admissions (2962 homes), reported in **Table 9.2**.

In total, 26,719 records were available, after excluding cases where records were blank (n=14), there were 26,705 admission records for analysis. After removing transfers between care homes and cases where admission source was not known, 21,368 records were eligible for inclusion. Transfers accounted for the majority of excluded records (74%) (**Figure 9.1**).

**Figure 9.1: Identifying care home admissions**




### 9.3.3.2 Aggregate data summary

**Table 9.5** summarises the findings extracted from the aggregate part of the data. The majority (56.7%) of admissions were recorded as being from hospital. Data were relatively evenly distributed between the census years, with around a third of admissions from each year.

The vast majority (96.4%) of admissions are to care homes where the Care Inspectorate subtype is 'older people'. Those admitted to a care home providing care for those with mental health problems were more likely to have been admitted from hospital (74.7%). Those admitted to a care home providing care for individuals with learning disabilities were more likely to have been admitted from home (68.8%). Most admissions were to privately-owned care homes (77.1%). Care homes vary significantly in size (range 2-180 places), with those admitted from hospital to care homes with a mean of 10.0 more places (95% CI 9.2 – 10.8).

**Table 9.5: Descriptive analysis of aggregate data by source of admission**

| | | **Hospital** No=12,113 N | **Home** No =9,255 N | **TOTAL** No =21,368 N (% of total) |
|---|---|---|---|---|
| **Census year** | 2013/14 | 3854 | 3040 | 6894 (32.3) |
| | 2014/15 | 3987 | 2868 | 6855 (32.1) |
| | 2015/16 | 4272 | 3347 | 7619 (35.7) |
| **Care home subtype** | Older People | 11775 | 8821 | 20596 (96.4) |
| | Mental Health Problems | 180 | 61 | 241 (1.1) |
| | Learning disabilities | 59 | 130 | 189 (0.9) |
| | Physical & Sensory Impairment* | 51 | 50 | 101 (0.5) |
| | Other** | 48 | 193 | 241 (1.1) |
| **Service type** | Private | 9942 | 6532 | 16474 (77.1) |
| | Voluntary or Not for Profit | 1219 | 1423 | 2642 (12.4) |
| | Local Authority and health board | 952 | 1300 | 2252 (10.5) |
| **Capacity** | Range | 2-180 | 2-180 | - |
| | Mean [SD] | 59.2 [31.9] | 49.2 [28.0] | - |
| | Median [IQR] | 53.0 [38] | 43.0 [28] | - |
| | MISSING | 8 | 21 | 29 |

** Physical & Sensory Impairment 2013/14, 2014/15 – renamed Physical disabilities 2015/16*

*** Other – aggregated category including alcohol & drug misuse, parents, respite care and short breaks*

**Table 9.6** provides additional information from the aggregate dataset on the main provision of the care home and the client needs it can also cater for (e.g. palliative and end-of-life care). Changes in coding between census years necessitate presentation of data by year, rather than as an aggregate comparison. The data summarise the care provided by the care home, rather than the specific care needs of the resident who has been admitted.

**Table 9.6: Descriptive analysis of aggregate data by year and source of admission**

| | 2013/14 Total=6894 | | 2014/15 Total=6855 | | 2015/16 Total=7619 | |
|---|---|---|---|---|---|---|
| | From Hospital N=3854 N (%) | From Home N=3040 N (%) | From Hospital N=3987 N (%) | From Home N=2868 N (%) | From Hospital N=4272 N (%) | From Home N=3347 N (%) |
| **Main provision of care home** | | | | | | |
| Older people | 3250 (84.3) | 2467 (81.2) | 3390 (85.0) | 2334 (81.4) | - | - |
| Older people – dementia | - | - | - | - | 1489 (34.9) | 1129 (33.7) |
| Older people – frailty | - | - | - | - | 2524 (59.1) | 1970 (58.9) |
| Dementia | 324 (8.4) | 245 (8.1) | 367 (9.2) | 333 (11.6) | - | - |
| Physical disability or illness | 26 (0.7) | 32 (1.1) | 59 (1.5) | 55 (1.9) | 87 (2.0) | 44 (1.3) |
| Mental health (not dementia) | 40 (1.0) | 14 (0.5) | 58 (1.5) | 24 (0.8) | 58 (1.4) | 18 (0.5) |
| Substance related* | 21 (0.5) | 62 (2.0) | 54 (1.4) | 67 (2.3) | 21 (0.5) | 75 (2.2) |
| Learning difficulties | 17 (0.4) | 46 (1.5) | 18 (0.5) | 34 (1.2) | 0 | 35 (1.0) |
| Acquired brain injury | 13 (0.3) | 4 (0.1) | 5 (0.1) | X | 18 (0.4) | 26 (0.8) |
| Visual impairment | 16 (0.4) | 6 (0.2) | 17 (0.4) | 8 (0.3) | 15 (0.4) | 8 (0.2) |
| Other (autism & palliative care) | X | 10 (0.3) | X | 0 | 0 | 0 |
| MISSING | 144 | 154 | 18 | 9 | 49 | 41 |
| **Client needs care home can accommodate** | | | | | | |
| Acquired brain injury | 600 (15.6) | 497 (16.3) | 804 (20.2) | 526 (18.3) | 677 (15.8) | 457 (13.7) |
| Dementia | 1773 (46.0) | 1423 (46.8) | 3257 (81.7) | 2314 (80.7) | - | - |
| Hearing impairment | 1563 (40.6) | 1279 (42.1) | 2458 (61.7) | 1783 (62.2) | 2719 (63.6) | 1947 (58.2) |
| Learning disability | 1410 (36.60 | 1125 (37.0) | 1214 (30.4) | 837 (29.2) | 1130 (26.5) | 825 (24.6) |
| Older people | 3630 (94.2) | 2751 (90.5) | 3867 (97.0) | 2738 (95.5) | - | - |
| Older people – dementia | - | - | - | - | 4047 (94.7) | 3079 (92.0) |
| Older people – frailty | - | - | - | - | 3929 (92.0) | 3027 (90.4) |
| Palliative & end of life care | 3337 (86.6) | 2466 (81.1) | 3622 (90.8) | 2501 (87.2) | 3670 (85.9) | 2695 (80.5) |
| Physical disability or illness | 3268 (84.8) | 2419 (79.6) | 3569 (89.5) | 2380 (83.0) | 3208 (75.1) | 2272 (67.9) |
| Sensory impairment | 2932 (76.1) | 2373 (78.1) | 3091 (77.5) | 2272 (79.2) | - | - |
| Visual impairment | 3316 (86.0) | 2473 (81.3) | 3450 (86.5) | 2416 (84.2) | 3022 (70.7) | 2181 (65.2) |

** Defined as: alcohol, alcohol brain injury, drug dependency, Korsakoffs; X – removed underlying value due to small numbers*

*- denotes where category not reported in that census year*

### 9.3.4 Demographics & funding

**Table 9.7** summarises the individual resident data for both groups. The majority of admissions were of older women of white ethnic origin. Those admitted from hospital were older by 0.44 years (95% CI 0.11-0.76), compared with those admitted from home.

Around two-thirds of admissions in both groups received Local Authority funding. Of those (n=6,937) funding their own care, 86% received the free personal care allowance. A much greater proportion of those admitted from hospital received free nursing care compared with those admitted from home (67.2% vs 45.8%; 21.3% higher 95%CI 19.0-23.6% higher).

**Table 9.7: Descriptive analysis of individual admissions data**

| | | **From Hospital** N=12,113 N (%) | **From Home** N=9,255 N (%) |
|---|---|---|---|
| Sex | Female | 7614 (62.9) | 6248 (67.5) |
| | Male | 4494 (37.1) | 3000 (32.4) |
| | MISSING | 1 | 5 |
| Age at admission | Mean [SD] | 82.1 [10.7] | 81.9 [12.8] |
| | Median [IQR] | 84 [11] | 85 [12] |
| | <60 | 472 (3.9) | 500 (5.4) |
| | 60-69 | 675 (5.6) | 422 (4.6) |
| | 70-79 | 2423 (20.0) | 1682 (18.2) |
| | 80-89 | 5734 (47.3) | 4307 (46.5) |
| | 90-99 | 2694 (22.2) | 2241 (24.2) |
| | >100 | 108 (0.9) | 90 (1.0) |
| | MISSING | 7 | 13 |
| Ethnicity | White | 11986 (98.2) | 9046 (97.7) |
| | Other ethnic group | 20 (0.2) | 25 (0.3) |
| | Not disclosed | 42 (0.3) | 27 (0.3) |
| | Not known | 62 (0.5) | 60 (0.6) |
| | MISSING | 93 (0.8) | 97 (1.1) |
| Mainly or wholly funded | Local Authority | 7754 (64.0) | 5971 (64.5) |
| | Private | 3710 (30.6) | 3227 (34.9) |
| | NHS | 643 (5.3) | 42 (0.5) |
| | MISSING | 6 | 15 |
| If self-funding (i.e. private) | **Free personal care** | | |
| | Yes | 3290 (88.7) | 2690 (83.3) |
| | No | 419 (11.3) | 536 (16.6) |
| | MISSING | 1 | 1 |
| | **Free nursing care** | | |
| | Yes | 2492 (67.2) | 1479 (45.8) |
| | No | 1206 (32.5) | 1742 (54.0) |
| | MISSING | 12 | 28 |

*Table 9.7 continued overleaf*

***Table 9.7 continued***

| | | | |
|---|---|---|---|
| Month of admission | April | 1054 (8.7) | 818 (8.8) |
| | May | 986 (8.1) | 787 (8.5) |
| | June | 975 (8.0) | 763 (8.2) |
| | July | 967 (8.0) | 741 (8.0) |
| | August | 908 (7.5) | 739 (8.0) |
| | September | 848 (7.0) | 723 (7.8) |
| | October | 910 (7.5) | 741 (8.0) |
| | November | 1017 (8.4) | 767 (8.3) |
| | December | 1030 (8.5) | 802 (8.7) |
| | January | 1050 (8.7) | 818 (8.8) |
| | February | 1210 (10.0) | 798 (8.6) |
| | March | 1158 (9.6) | 758 (8.2) |
| Alive and resident in same care home | | 9051 (74.7) | 7316 (79.0) |
| Death within same census year | | 2209 (18.2) | 1072 (11.6) |
| Transfer within same census year | | 438 (4.4) | 278 (3.4) |
| Discharge within census year | | 415 (4.4) | 589 (7.5) |
| Reason for discharge | Hospital | 257 (61.9) | 148 (25.1) |
| | Other/not known | 43 (10.4) | 72 (12.2) |
| | Own home | 96 (23.1) | 330 (56.0) |
| | Sheltered/supported accommodation | 19 (4.6) | 39 (6.6) |

### 9.3.5 Care home activity

Data on admissions seems relatively constant throughout a year, with a greater number of admissions in the winter months. The census data allow for monitoring from April to March of the following year.

Of those admitted in each census year, the majority of admissions were alive and still in the same care home to which they were admitted. A higher proportion of those admitted from hospital died within the year (18.2% *vs* 11.6%) than those admitted from home.

Discharges were more common among those admitted from home (7.5% *vs* 4.4%) and were more likely be to 'own home'. Individuals admitted to the care home from hospital were more likely to be readmitted to hospital if discharged compared with those admitted from home, Between 3.4-4.4% of individuals were transferred to another care home during the census year.

### 9.3.6 Care needs

The care needs for each admission are summarised in **Table 9.8**. Those admitted can be recorded as having as many needs as are applicable. These are the proportions of individuals admitted from hospital compared with those admitted from home who have each need. Those admitted from hospital were more likely to require nursing care (74.9% *vs* 52.6%) and to have another physical disability or illness (49.5% *vs* 35.1%). Those with acquired brain injury and those with mental health problems were more likely to have been admitted from hospital and those with learning disabilities were more likely to have been admitted from home. Medically-diagnosed dementia was prevalent among both those admitted from hospital (51.4%) and those admitted from home (48.5%).

**Table 9.8: Care needs of admissions from hospital *versus* those admitted from home** (% of all admissions in each group)

| | **Admitted from Hospital** N=12,113 N (%) | **Admitted from Home** N=9,255 N (%) |
|---|---|---|
| Nursing care | 9069 (74.9) | 4870 (52.6) |
| Other physical disability or chronic illness | 6001 (49.5) | 3253 (35.1) |
| Dementia – medically diagnosed | 5880 (48.5) | 4756 (51.4) |
| Visual impairment | 1695 (14.0) | 1447 (15.6) |
| Hearing impairment | 1225 (10.1) | 957 (10.3) |
| Dementia – not medically diagnosed | 862 (7.1) | 770 (8.3) |
| Mental health problems | 844 (7.0) | 402 (4.3) |
| Acquired brain injury | 268 (2.2) | 72 (0.8) |
| Learning disability | 135 (1.1) | 264 (2.9) |

### 9.3.7 Analysis of findings by geographical boundaries

There are three geographical comparisons which are possible: Health Board area of care home; Local Authority of care home and; Local Authority funding care home placement.

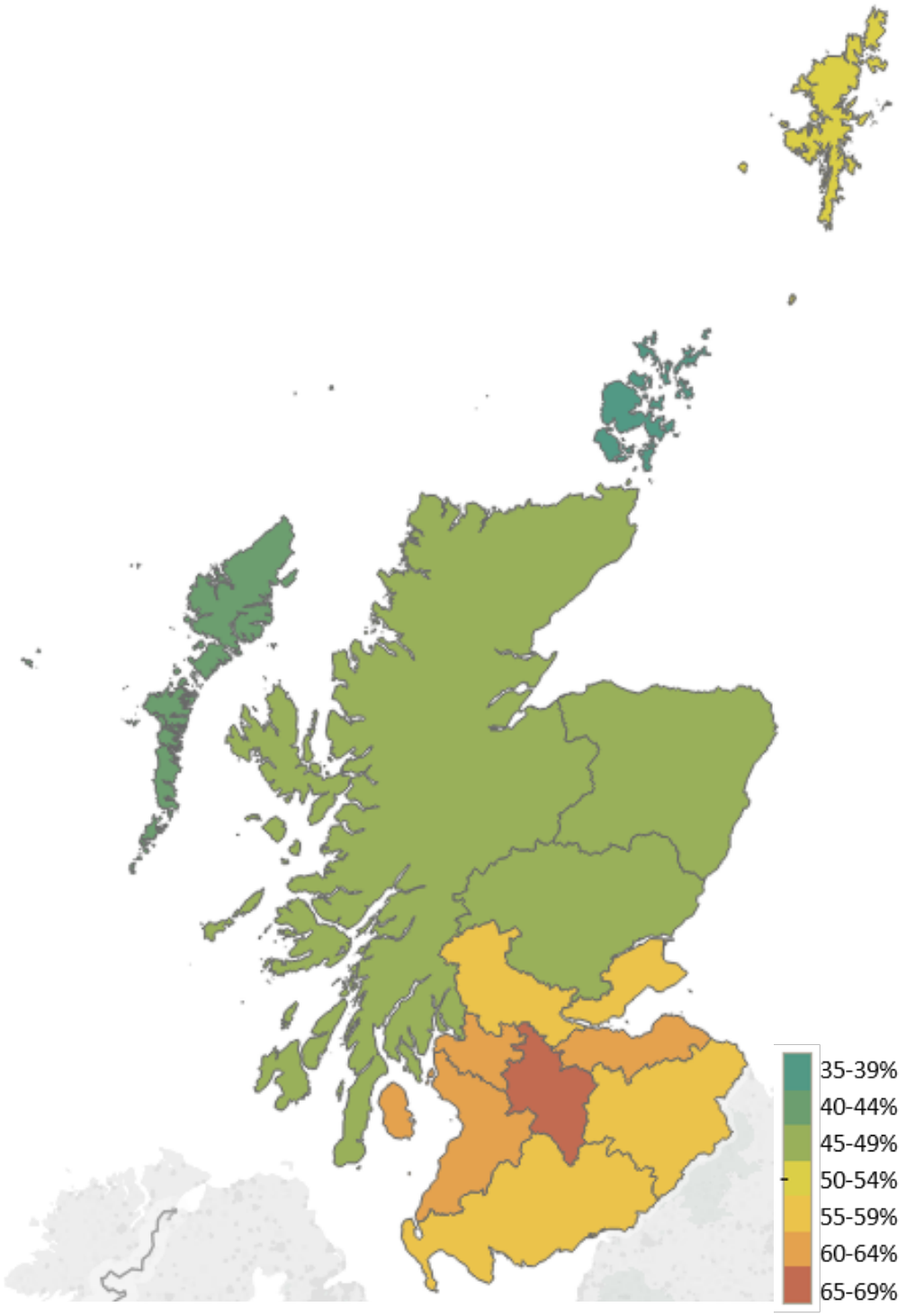
#### 9.3.7.1 Health Board area of care home

**Table 9.9** includes the number of admissions to care homes in each Health Board area and the number and proportion where the admission was from hospital. NHS Greater Glasgow & Clyde has the largest number of admissions (n=5,049). The proportion of those admitted from hospital varies from 35.9% in NHS Orkney to 64.8% in NHS Lanarkshire. Health Board data have also been displayed in map format to allow comparison of the proportion of admissions in each area where the individual was admitted from hospital (**Figure 9.2**).

**Table 9.9: Admissions to care homes in each Health Board area in Scotland with number and proportion of admissions from hospital**

| Health board | Total number of admissions | N (%) from hospital |
|---|---|---|
| Greater Glasgow & Clyde | 5049 | 3085 (61.1) |
| Lothian | 2359 | 1408 (59.7) |
| Grampian | 2370 | 1146 (48.4) |
| Lanarkshire | 2091 | 1354 (64.8) |
| Tayside | 1888 | 885 (46.9) |
| Ayrshire & Arran | 1786 | 1078 (60.4) |
| Fife | 1724 | 998 (57.9) |
| Highland | 1603 | 789 (49.2) |
| Forth Valley | 1032 | 593 (57.5) |
| Dumfries & Galloway | 832 | 473 (56.9) |
| Borders | 342 | 187 (54.7) |
| Western Isles | 113 | 45 (39.8) |
| Orkney | 92 | 33 (35.9) |
| Shetland | 59 | 31 (52.5) |
| MISSING | 29 | - |

**Figure 9.2: Map displaying proportion of care home admissions from hospital by Health Board area**



To help to contextualise the Health Board admissions data, admissions recorded in 2015/16 are presented in **Table 9.10**, with the estimated adult population and rate of care home admissions from hospital and home. These range from a rate of 4.7 to 11.9 per 10,000 adults from hospital and 4.2 to 10.5 per 10,000 adults from home.

**Table 9.10: Rate of care home admissions from hospital and home in 2015/16 data**

| Health Board area | Total number of care home admissions in 2015/16 | Estimated adult population in 2016* | Rate of care home admissions from hospital per 10,000 adults | Rate of care home admissions from home per 10,000 adults |
|---|---|---|---|---|
| Greater Glasgow & Clyde | 1513 | 1,161,370 | 7.9 | 5.1 |
| Lothian | 863 | 880,000 | 5.6 | 4.2 |
| Lanarkshire | 854 | 656,490 | 8.4 | 4.6 |
| Grampian | 870 | 588,100 | 6.9 | 7.9 |
| Tayside | 745 | 415,470 | 8.6 | 9.3 |
| Ayrshire & Arran | 705 | 370,560 | 11.9 | 7.1 |
| Fife | 618 | 370,330 | 10.3 | 6.4 |
| Highland | 600 | 321,900 | 8.6 | 10.0 |
| Forth Valley | 331 | 304,480 | 6.0 | 4.9 |
| Dumfries & Galloway | 268 | 149,520 | 9.4 | 8.5 |
| Borders | 145 | 114,530 | 7.0 | 5.7 |
| Western Isles | 39 | 26,900 | 6.3 | 8.2 |
| Orkney | 36 | 21,850 | 5.9 | 10.5 |
| Shetland | 23 | 23,200 | 4.7 | 5.2 |

**Data from NRS Mid-Year Population Estimates National Records of Scotland, 2017b*

#### 9.3.7.2 Local Authority area of care home

Local Authority areas overlap Health Board boundaries and thus provide additional detail. The total number of admissions in the three-year period varies significantly between Local Authorities (range 59 in Shetland to 2432 in Glasgow City). The proportion of those admitted from hospital varies from 35.9% in Orkney to 66.6% in North Ayrshire. **Table 9.11** presents admissions by Local Authority, including the number and proportion admitted from hospital and the ranking based on the highest proportion admitted from hospital.

**Table 9.11: Admissions to care homes in each Local Authority area in Scotland with number and proportion of admissions from hospital**

| Local authority | Total number of admissions | N (%) from hospital | Rank of % from hospital |
|---|---|---|---|
| Glasgow City | 2432 | 1570 (64.5) | 4 |
| Fife | 1724 | 998 (57.9) | 10 |
| Highland | 1320 | 638 (48.3) | 26 |
| Edinburgh City | 1318 | 831 (63.1) | 7 |
| South Lanarkshire | 1197 | 752 (62.8) | 8 |
| Aberdeenshire | 1170 | 493 (42.1) | 28 |
| Renfrewshire | 1072 | 713 (66.5) | 2 |
| North Lanarkshire | 983 | 652 (66.3) | 3 |
| Dumfries & Galloway | 832 | 473 (56.9) | 15 |
| Aberdeen City | 751 | 397 (52.9) | 20 |
| Angus | 650 | 236 (36.3) | 31 |
| Dundee City | 647 | 327 (50.5) | 23 |
| South Ayrshire | 645 | 367 (56.9) | 14 |
| North Ayrshire | 617 | 411 (66.6) | 1 |
| Perth & Kinross | 614 | 328 (53.4) | 19 |
| Falkirk | 548 | 347 (63.3) | 6 |
| East Ayrshire | 524 | 300 (57.3) | 11 |
| East Dunbartonshire | 471 | 224 (47.6) | 27 |
| West Lothian | 451 | 246 (54.5) | 17 |
| Moray | 449 | 256 (57.0) | 13 |
| Inverclyde | 434 | 248 (57.1) | 12 |
| Scottish Borders | 342 | 187 (54.7) | 16 |
| Midlothian | 301 | 189 (62.8) | 9 |
| East Lothian | 289 | 142 (49.1) | 25 |
| Argyll & Bute | 282 | 151 (53.5) | 18 |
| East Renfrewshire | 280 | 145 (51.8) | 22 |
| West Dunbartonshire | 276 | 137 (49.6) | 24 |
| Stirling | 265 | 105 (39.6) | 30 |
| Clackmannanshire | 219 | 141 (64.4) | 5 |
| Eilean Siar *(Outer Hebrides)* | 113 | 45 (39.8) | 29 |
| Orkney | 92 | 33 (35.9) | 32 |
| Shetland | 59 | 31 (52.5) | 21 |

#### 9.3.7.3 Local Authority funding care home placement

The final geographical comparison which can be made is based on Local Authority funding (**Table 9.12**). If an individual is funded by their Local Authority, or if they pay their care home fees *via* their Local Authority, this is recorded. These represent ~65% of admissions included in the census data. The Local Authority funding the care is most likely to be that in which the individual lived previously, but it might not be that of the care home into which they move.

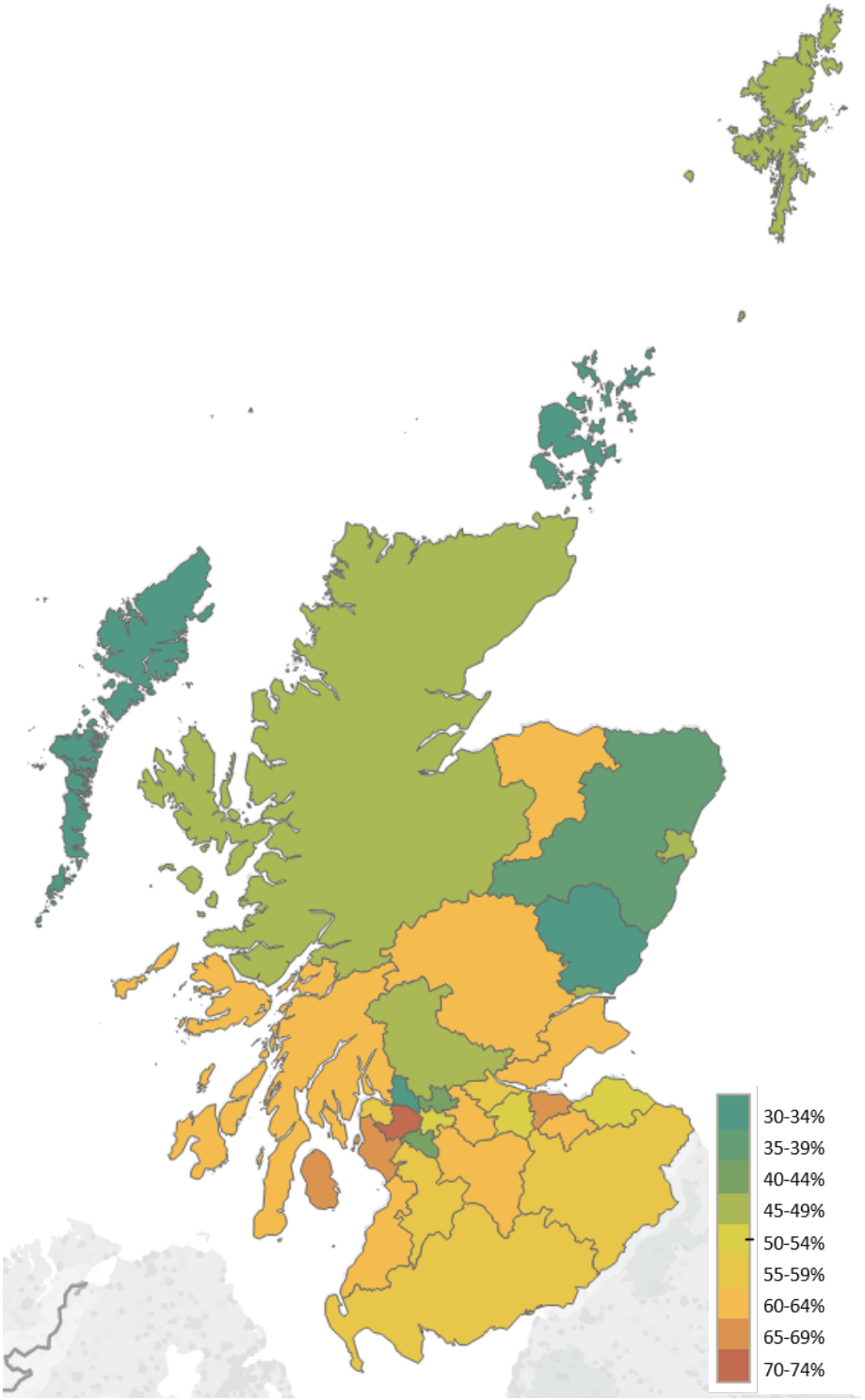
**Table 9.12: Admissions funded by Local Authorities, including the number and proportion admitted from hospital**

| Local authority | Total number of funded admissions | N (%) from hospital |
|---|---|---|
| Glasgow City | 1583 | 874 (55.2) |
| Fife | 935 | 591 (63.2) |
| Highland | 901 | 435 (48.3) |
| South Lanarkshire | 876 | 544 (62.1) |
| North Lanarkshire | 734 | 479 (65.3) |
| Dumfries & Galloway | 704 | 410 (58.2) |
| Aberdeenshire | 683 | 285 (41.7) |
| Renfrewshire | 648 | 479 (73.9) |
| Edinburgh City | 602 | 409 (67.9) |
| Aberdeen City | 503 | 250 (49.7) |
| Dundee City | 454 | 217 (47.8) |
| Falkirk | 445 | 266 (59.8) |
| East Ayrshire | 440 | 250 (56.8) |
| North Ayrshire | 428 | 283 (66.1) |
| South Ayrshire | 328 | 199 (60.7) |
| Inverclyde | 325 | 192 (59.1) |
| Angus | 310 | 111 (35.8) |
| West Lothian | 300 | 158 (52.7) |
| Perth & Kinross | 299 | 184 (61.5) |
| West Dunbartonshire | 279 | 145 (52.0) |
| Moray | 263 | 159 (60.5) |
| Scottish Borders | 262 | 150 (57.3) |
| Argyll & Bute | 203 | 123 (60.6) |
| East Lothian | 187 | 99 (52.9) |
| Midlothian | 176 | 111 (63.1) |
| East Dunbartonshire | 163 | 75 (46.0) |
| East Renfrewshire | 160 | 72 (45.0) |
| Stirling | 142 | 52 (36.6) |
| Clackmannanshire | 139 | 92 (66.2) |
| Eilean Siar *(Outer Hebrides)* | 96 | 33 (34.4) |
| Orkney Islands | 85 | 30 (35.3) |
| Shetland Islands | 45 | 23 (51.1) |
| Outwith Scotland | 26 | 17 |
| MISSING | 1 | 1 |

The numbers of Local Authority-funded admissions vary between Local Authorities (range 45-1583). The proportion of those funded admissions admitted from hospital varies from 34.4% in Eilean Siar to 73.9% in Renfrewshire. These findings have been displayed in map format to compare the proportion of those receiving Local Authority funding who are admitted from hospital in each Local Authority area (**Figure 9.3**).

**Figure 9.3: Map displaying proportion of care home admissions from hospital funded by Local Authority**

*Footnote: Map displays the 31 Integration Authorities, rather than the 32 Local Authority areas. This merges*




*Clackmannanshire & Stirling as no shapefile was freely available with Local Authority boundaries displayed*

### 9.3.8 Discussion

The descriptive analysis reported in this Chapter is the first to use individual long-stay resident data submitted as part of the SCHC. This provides a cohort of more than 21,000 admissions over a three-year period whose status has been divided into those admitted from hospital compared with those admitted from home. There is evidence of variation between the population of adults admitted from hospital compared with those admitted from home, with respect to their comorbidities, dependency and mortality. There is also variation across Scotland with respect to the rates of admission to care home, the proportion admitted from hospital and their funding.

#### 9.3.8.1 Key findings

These data provide valuable insights into admissions to Scotland's care homes. The 12,113 (56.7%) admitted from hospital are older, have higher mortality (deaths within the census year) (18.2% *vs* 11.6%) and higher rates of subsequent hospitalisation (7.5% *vs* 4.4%). This may reflect the original reason for hospitalisation and suggest those admitted from hospital may be a frailer group of individuals.

Those admitted from hospital seem to be more dependent in care needs, with a higher proportion eligible to receive State-funded nursing care allowance (67.2% *vs* 45.8%). More individuals categorised with physical disabilities and chronic illness, brain injury and mental health problems were admitted from hospital. Again, this may reflect the medical complexity of those who required hospital admission originally. Fewer individuals admitted from hospital had a learning disability (1.1% *vs* 2.9%). This may suggest that these individuals' increasing care needs can be more predictably planned and care home admission arranged from the community, without a hospitalisation crisis.

Dementia was prevalent in both groups, affecting 55.6% and 59.6% of admissions from hospital and home respectively, including those with a formal diagnosis and those the staff considered to have dementia. These combined figures are lower than quoted estimates (>80%) of the prevalence of dementia (diagnosed and undiagnosed) among care home residents (Alzheimer's Society, 2013).

There is evidence of geographical variation with respect to the proportion of admissions from hospital and extent of care home funding. The proportion of those in each Health Board area admitted from hospital varied from 35.9% to 64.8%. Local Authority data provide a more detailed picture of the variation within the Health Board areas. Local Authority funding also varies, with 34.4% to 73.9% of the Local Authority-funded admissions being admitted directly from hospital. Such variation is interesting and requires greater scrutiny to explore its meaning and adjust for regional differences in population structure.

#### 9.3.8.2 Limitations and challenges during analysis

The analysis has been performed on the basis of admissions rather than individuals, because it is based only on data from the SCHC and therefore individuals may be included multiple times. There is no consistent identifier variable used between the years of the census data and, within

the same census year, individuals may appear more than once. As it was not possible to identify which records relate to the same individual resident, it was decided to include all available data. This approach limits the ability to consider outcomes such as mortality, discharge and transfer outwith the census year in which an admission occurred.

Univariate descriptive analyses cannot take account of the likely confounding by related variables. Many factors are not included in the SCHC which may influence rates of care home admission and the likelihood of admission directly from hospital: for example, deprivation, rurality and population structure. Adjusting proportions of admissions from home and hospital based on the adult population demonstrates the need to adjust the data to make valid comparisons. Adults were selected as the denominator because the care home population and SCHC data include those aged under 65. The population aged≥ 65 years varies between Health Board areas, from 16% in Lothian and Greater Glasgow & Clyde to 25% in the Western Isles and Dumfries & Galloway (National Records of Scotland, 2017b), so it is arguable that future analyses should stratify the care home population by age. Analysis based on Health Board and Local Authority of the care home summarises where the individual lives now, but this may not necessarily be the same as where they lived before care home admission, nor can it be automatically assumed that those admitted from hospital were admitted from the hospital in the same Health Board area. Linked data analysis could incorporate geographical data about residence before care home admission and the hospital from where the individual was admitted.

Data quality with respect to the completeness of the census data and representativeness of the homes which submit data remains a concern. Although progress has been made in estimating returning and non-returning homes, there are differences with respect to submitted data and these will inevitably introduce bias. It has not been possible to determine the nature of this bias, other than by Local Authority, but this still requires further exploration. This is most problematic when reporting data on geographical variation where lack of submitted information affects the data presented, as the analysis is based on calculating proportions from the available data.

A particular challenge in presenting the data comes from the changes in recording of variables between the census years, for example in categorising the main provision of the care home. This limits the potential to aggregate multiple years of data, but is important to reflect the underlying submitted data, particularly as definitions are lacking, making aggregation inappropriate. A related concern is how the data are entered within the care home and what the variables mean to the staff submitting them. Understanding the source of the data is important in interpreting them appropriately and this also requires further exploration.

Finally, the SCHC does not include variables which are of interest to researchers regarding the health and function of care home residents, e.g. continence, functional status including activities of daily living. There has been some pilot work conducted in 65 care homes, using the Indicator of Relative Need (IoRN) data to describe trends in the dependency in the care home population over time (NHS National Services Scotland, 2016b). The IoRN is a dependency measure developed in Scotland for use in social care which combines an assessment of mobility, personal care, mental health and bowel care, with grading need from category A1 to I (Canny *et al*., 2016, Joint Improvememt Team, 2018). This may be a potential additional variable to incorporate into future data collection. The value of any information collected and recorded must be justified

based on planned usage of the data however and a robust case made for any new variables, as returns take time for care home staff to complete.

## 9.4 DEVELOPING A DATA LINKAGE PROJECT USING THE SCOTTISH CARE HOME CENSUS

The SCHC data has utility as a novel data source to explore care home admissions. Indexing the data – the process to create a single identifier variable which is common within and between years of data – is the first step as it allows analysis by individual. This process is also required to link the SCHC data to other data sources. Linkage has the potential to add value to the data collected, by the ability to ascertain information prior to care home admission and develop a greater understanding around comorbidities, deprivation and geography. Linkage also offers the opportunity to evaluate the quality and veracity of the data for significant events, such as hospitalisations and deaths, as it is possible to sequence events in other sources. Therefore, a project was developed based around linking the SCHC data in order to explore new care home admissions from hospital compared with those from home. This project is still in progress and awaiting data, so only the methods are described here.

### 9.4.1 Aim & objectives

This project aims to identify the patterns and predictors of care home admission from hospital across Scotland using routinely-collected linked health and social care data sources.

This will be achieved through the following specific objectives:

(i) To establish the best way to identify care home residents in routinely-collected data.
(ii) To establish the accuracy of dementia diagnosis coding in the care home census, compared with other routinely-collected data.
(iii) To describe and compare rates of admission to care home from hospital *vs* the community by region and explore any geographical variation.
(iv) To identify predictors of care home admission from hospital *vs* the community with particular interest in the role of dementia and delirium.

### 9.4.2 Proposed methods

#### 9.4.2.1 Overall design

The primary purpose is to conduct a retrospective cohort study using linked health and social care data to describe the patterns of care home admission from hospitals across Scotland and to identify predictors for these admissions. Before this work can be done, however, it is necessary to evaluate the underlying accuracy and completeness of the data sources which identify care home residents, as this has not been considered before and preliminary work has suggested it is challenging (Burton and Guthrie, 2018, Housley *et al*., 2018). Dementia is known to be a significant factor in determining need for institutional care (Hajek *et al*., 2015, Luppa *et al*.,

2010), however dementia diagnostic coding in Scotland is known to be sub-optimal (Russ *et al*., 2012, Russ *et al*., 2013). As a consequence, understanding the accuracy of dementia status is important before considering this a predictor variable. Exploring the quality of both these aspects will allow more certainty in the completeness and potential gaps in findings. The project was therefore planned in three stages described in Section 9.4.2.4.

#### 9.4.2.2 Setting and participants

All data were collected in Scotland and generated through the individual's use of health and social care services. Information is primarily identified using the CHI number, allocated to an individual when they register in primary care. Care home residents and their families are informed by the care home staff about their data being used for the care home census return.

#### 9.4.2.3 Data sources

This project uses data from a total of seven data sources which will be described briefly below.

**Scottish Care Home Census**: individual long-stay resident data will be used to identify new care home admissions in each census year and to extract variables about the resident and the care home to which they have been admitted.

**National Records of Scotland (NRS) Deaths**: to be used to identify date of death to help establish the status of individuals identified and compare survival in those admitted from home with those admitted from hospital.

**CHI File**: to be used to extract key demographic information, including adjusted date of birth, and derive geographical variables concerning residency. The CHI Institution Flag will also be extracted where it indicates a residential home (93) or nursing home (98).

**Scottish Morbidity Record (SMR) 01 Inpatients and Day Cases**: to be used for data on inpatient and day-case hospital usage, diagnoses, length of stay and to evaluate the data on where an individual was admitted from and discharged to.

**Scottish Morbidity Record (SMR) 04 Mental Health**: to be used for data on specialist psychiatry service usage, diagnoses and to evaluate the data on where an individual was admitted from and discharged to.

**Prescribing Information System (PIS)**: community dispensing data, includes date a prescription was dispensed, the number of items and information on specific prescribed medications by BNF chapter (Alvarez-Madrazo *et al*., 2016). The PIS data contains a Care Home Flag variable, derived from the CHI Care Home Flag, which identifies if the prescription was for an individual living at a care home address.

**Scottish Patients at Risk of Readmission and Admission (SPARRA)**: the SPARRA dataset has been created to inform a risk prediction tool to help identify individuals at highest risk of admission and readmission, based on their patterns of healthcare use (Information Services Division Scotland and NHS National Services Scotland, 2010). In addition to the specific SPARRA

score, this dataset also contains long-term condition flags and information on outpatient use, emergency department attendances and admissions.

A comprehensive list of all requested variables was prepared, incorporating variables from the datasets described above.

#### 9.4.2.4 Study stages

**Stage one: identifying care home residents**

This includes individuals living in a care home in Scotland in each of the defined years of interest (2010/11 – 2015/16). Individuals will be identified for inclusion if they have a record in the SCHC, the CHI Institution Flag indicates care home residency, a dispensed prescription has a care home flag or if they are discharged to a care home using SMR01 or SMR04. These data sources will be compared to analyse **how best to identify care home residents in the routinely-collected datasets** and to describe data accuracy and completeness. This will require calculating the number of residents identified in each data source and the overlap between sources, looking at levels of agreement and attempting to identify misclassifications. This will help to inform care home research and studies attempting to include care home admission as an outcome measure, by clarifying the relative value and accuracy of the available data sources.

**Stage two: identifying care home residents with dementia**

Using the individuals identified in Stage one as care home residents, information on dementia with be sought from other data sources. This includes the SCHC variables for dementia, a dispensed prescription of a cognitive-enhancing medication, SMR01 or SMR04 diagnosis of dementia or record in the SPARRA data for Alzheimer's disease or dementia. These data sources will be compared to analyse **how best to identify dementia among care home residents in routinely-collected datasets** and to describe accuracy and completeness. Using the approach described above, this will require calculation of those with a dementia diagnosis in each data source and the overlap between them. This will help to inform the wider dementia research effort by establishing the usefulness of SCHC data specifically, as a novel data source, and evaluating dementia ascertainment among care home residents.

**Stage three: exploring the patterns and predictors of care home admission from hospital compared with admission from the community**

These analyses will focus only on individuals identified as new admissions to care homes between 2013/14 – 2015/16. The sample will be divided into those admitted from home and those admitted from hospital and will repeat the descriptive analyses described in Section 9.3. Additional information will be sought and described from three years' worth of data prior to care home admission concerning deprivation, dispensed community prescribing, long-term conditions, hospital admissions and attendances. These will be supplemented by geographic analysis to explore questions around access to services.

These data can be used to **evaluate the quality of hospital discharge coding across Scotland** with respect to care home residency. The patterns of admission from hospital and home will be compared across Scotland to **explore the geographical variation in rates** identified in the unlinked analyses. Bivariate and multivariate models will be created **to explore predictors of care home admission from hospital compared with those admitted from home**.

### 9.4.3 Project progress

This project has been conceived, developed, funded and received permissions to proceed since August 2015, with provision of the complete dataset awaited as at March 2018. The time taken primarily reflects the realities of trying to use a social care data source which required additional assurances during the permissions process and more complex procedures required to link it to health data. The key project milestones are presented briefly.

#### 9.4.3.1 Funding

An application was submitted to the Scottish Informatics and Linkage Collaboration (SILC) *via* a Scottish Government process to prioritise work considered relevant to the Analytical Leadership Group objectives (Scottish Government, 2016e). This was accompanied by a draft Privacy Impact Assessment. Funding was awarded in January 2016 to cover the costs of the eDRIS support service, storage of the data and the costs of NRS advisory and data linkage services (Appendix 9.1).

#### 9.4.3.2 eDRIS

The electronic Data Research and Innovation Service (eDRIS) has been designed to support the process of researcher access to linked data. The project was assigned a Research Co-ordinator, who acted as the contact point for all queries with the Public Benefit and Privacy Panel (PBPP) application, indexing, linkage, data access and release of outputs from the SafeHaven.

#### 9.4.3.3 Stakeholder engagement

A key aspect of designing this project was the engagement of the relevant stakeholders. The SCHC is considered the primary focus of this research and the data are controlled by the Scottish Government Health & Social Care Analytical Division. It is collected by the Care Inspectorate and analysed by the Care Homes Team within ISD. Time was taken to engage with these key stakeholders to ensure that they all believed that the research was necessary and relevant so that any findings, particularly with respect to completeness, could be shared and addressed to improve data quality.

#### 9.4.3.4 Public engagement

The Scottish Dementia Clinical Research Network Patient and Public Involvement Group was consulted on the project. Its feedback was supportive and encouraging, particularly concerning the use of anonymised linked care home data:

> *"… this is probably the single most urgent and radical information that we must gather raw data on"*
>
> *"… an extremely important piece of research on many levels"*
>
> *"… the use of anonymised data will add to the veracity of this research and is necessary for this topic to have academic credibility".*

As there is no established patient and public involvement group in Scotland specifically for people living in care homes, contact was also made with the Scottish Care Home Research Group as additional stakeholders. It was in support of the project and wished to be kept updated regarding its progress. Comments from members included:

> *"I think it is an excellent piece of work, imaginatively using data to collect information about care homes and can only encourage and congratulate the research team on what they are doing."*
>
> *"It looks really interesting and will address gaps in knowledge. It is refreshing to look at things based on people known* via *the care home register as opposed to reliance on NHS data as that as we know gives an inaccurate reflection of whether or not people are living in care homes…. I'm delighted that this work is going ahead."*

These were summarised and incorporated into the Public Benefit and Privacy Panel application and used to help to justify the case for research support.

The project was also presented at the Edinburgh International Science Festival in April 2017. This provided the opportunity to respond to questions from members of the general public. Encouragingly the project was considered to represent the greatest public benefit, compared with the use of police and crime data to reduce drug dealing and the use of pregnancy and air pollution data to investigate the relationship between air pollution and foetal outcomes.

Once the data have been analysed and cleared for release, it is evident that this topic is highly relevant to the public so opportunities will be sought to discuss their meaning and next steps, including consulting the Administrative Data Research Centre Scotland Public Panel.

#### 9.4.3.5 Approvals & permissions

**NHS research ethics committee (REC) approval**: The project uses data which have already been collected and individual patient consent is not required. As the data need to be accessed by personnel not directly involved in clinical care, however, NHS REC approval was required. Permission was granted by the NHS Health Research Authority, South Central – Hampshire B Research Ethics Committee (REC Nº: 16.SC.0242) on 29/4/16, subject to approval by the Public Benefit and Privacy Panel. The work was granted full approval on 20/12/16 (Appendix 9.2).

**NHS research & development (R&D) approval**: R&D approval from NHS Lothian (Project Nº 2016/0129) was granted 22/12/16 (Appendix 9.3).

**Public benefit & privacy panel (PBPP) approval**: PBPP approval was required to allow the data to be obtained, linked and accessed. The application (Nº 1516-0438) was submitted in June 2016 and received conditional approval in December 2016, followed by full approval in March 2017 (Appendix 9.4).

The application was reviewed by both Tiers of the PBPP because of the assessment made of the data which were requested. Key queries were around the awareness of care home residents about the use of their data; the requirement for geographical variables; where, how and who was going to perform the geographical analyses; ethnic diversity; feedback of data quality issues and whether the project should be separated into two phases. It was interesting to note that the Panel felt that residents and families may wish to raise concerns about the study and use of the data from this setting. All of these queries were responded to over the intervening months and minor adjustments made to the variables requested, removing the most potentially identifiable geographical variables. It was also agreed the geographical analysis would be done by the Scottish Government geographer accessing the SafeHaven, rather than within the Scottish Government offices.

#### 9.4.3.6 Care home data indexing and linkage methodology

To enable the SCHC data to be linked to the other data sources, they needed to undergo indexing to match the records to the individual's CHI number. The indexing was performed by the NRS Indexing Team, which provided a report of the process followed and key aspects are summarised here. To facilitate the process, the ISD Care Homes Team supplied records with identifiable information to the NRS Indexing Team. Records were indexed for census years 2012/13-2015/16. Prior to this, the identifiers collected in the census were more limited and did not include forename and surname. As a result, indexing for 2010/11 and 2011/12 is to be performed separately.

In total, 146,152 records were submitted for indexing. These included the following identifiers: gender, Scottish postcode, day, month and year of birth, forename, surname and CHI number (where present from a previous linkage exercise). The completeness of each of these fields varied from 84-100%. The indexing was undertaken in stages, including pre-processing of the data to use Soundex codes to improve surname and forename matching. This was followed by use of BigMatch linkage software, developed in the US Bureau of Census (Yancey, 2007). BigMatch allows data to be blocked to identify best matching pairs between the data source and the CHI population spine. It allows multiple blocking criteria to be used to adapt to the available level of information, i.e. exact match in postcode, sex, date of birth and full name *vs* matches on first five characters of postcode, sex, year of birth and numeric part of Surname Soundex. Weights are then assigned based on the match probability. This means that records which have multiple identifiers are more readily matched than those with fewer, to try to reduce the likelihood of matching records which are not from the same individual. Deduplication was performed to ensure each individual CensusID is only assigned to a single individual, albeit they may have multiple census records as they appear in several years. Clerical review was conducted to evaluate the quality of the linkage, by comparing the original record with the results of the index match. This review resulted in estimated precision for the indexing exercise

of 98.6% (95%CI: 98.1-99.2%). Once indexing was complete, 131,229 records matched to a CHI record (89.8% of those submitted), representing 63,356 unique individuals. It is not yet possible to estimate the effects on the unlinked SCHC data, i.e. how many individual admission records could not be linked to CHI, as this total is derived from all data sources. It will, however, be possible to generate estimates once the linked data have been analysed.

## 9.5 SUMMARY OF PROJECT DEVELOPMENT

This first description of the SCHC data and progress towards using it for linked data analyses underlines the complexities of using routinely-collected social care data for research. A critical learning point has been using data for a different purpose from that for which it was originally collected. It is essential to understand the reasons for and mechanisms of data collection and how this may differ from the understanding of the researcher. To elaborate, the Care Inspectorate is primarily interested in regulatory aspects of service provision and practicalities, such as services which are cancelled or proposed for cancellation. The annual report on the SCHC data produced by ISD is designed to provide an overview of care home provision, but this relies on estimating and imputing data which have not been submitted in order to 'describe' the whole population. Research, such as that proposed here, is focused on analysis of the true data, submitted and returned, mindful of the limitations and extent of missing data and associated bias. Only completed data can be linked to other sources and explored.

Understanding what the data mean is an essential first stage before incorporating them into analyses. This requires time to be spent documenting the process and creating the meta-data. This will ensure that those wishing to use the data in future do not have to repeat these exploratory steps, instead applying the data to their own questions of interest. Analysis of the linked data has now commenced and will inform further research development and help to improve our understanding of this complex and vulnerable population.

# CHAPTER TEN
# General Discussion

This thesis has explored new care home admission following acute hospitalisation. Part One focused on identifying existing research and evaluating its quality and relevance. Part Two used quantitative and qualitative methods to investigate current clinical practice in a single large teaching hospital to try to better understand the lived experiences of those involved. Part Three used routinely-collected health and social care data to explore data quality and practice across Scotland.

Detailed discussions of the findings are presented within each of the chapters. This general discussion will highlight key findings and how these add to existing knowledge then present a summary of key strengths and limitations before concluding with future directions.

## 10.1 Key findings in context

### *10.1.1 Part One: Identifying relevant research*

The first objective of the thesis was to identify the predictors of care home admission following acute hospitalisation as reported in the published research literature. The systematic review identified 53 relevant studies from 16 countries comprising a total population of 1,457,881 participants in acute general medicine, general surgery and geriatric medicine; acute stroke; other acute specialist areas and; in rehabilitation. Quantitative synthesis of the results from 11 of the studies found that increased age (OR 1.02 per year age increase; 95%CI 1.00-1.04; moderate quality evidence), female sex (OR 1.04; 95%CI 1.03-1.92; low quality evidence), dementia & cognitive impairment (OR 2.14; 95%CI 1.24-3.70; low quality evidence) and functional dependency (OR 2.06; 95%CI 1.58-2.69; moderate quality evidence) were all associated with an increased risk of care home admission after hospitalisation.

The review is the first to focus on predictors of care home admission at discharge in hospitalised older adults. It found that fewer potential predictors have been considered in hospitalised cohorts compared with those living in the community (Luppa *et al*., 2010). Of particular note, continence was only considered in two of the studies. There is published survey evidence from Geriatricians that urinary and faecal incontinence increase the likelihood of referral to a nursing home (Grover *et al*., 2010). In addition, frailty was only considered in two of the studies, in spite of evidence of an association between frailty and care home admission in primary care (Clegg *et al*., 2016) and hospitalised older adults (Romero-Ortuno *et al*., 2017). More complex factors, such as relationships between care recipients and their carers were seldom considered, despite evidence from longitudinal data of their importance (Betini *et al*., 2017). The role of in-hospital models of care, such as access to comprehensive geriatric assessment, was not considered even though there is high quality evidence this can reduce the likelihood of care home admission (Ellis *et al*., 2017). Identifying 'new institutionalisation' after acute care remains an area of international research interest (Middleton *et al*., 2018). It is described as the first step to

developing programmes targeting those at risk to try to modify this outcome (Middleton *et al*., 2018).

Despite international variation in service provision, only two studies described the model of care provided in the care home setting.

The second objective was to develop methods to create a search filter to improve identification of the existing care home research literature.

The methodology described incorporates learning from existing published search filters and consensus critical appraisal checklist components.

The survey of international researchers (38% response rate (n=105 participants)) confirmed there was variation in terminology used. The subject heading term commonly applied by the databases when indexing care home research, 'Homes for the Aged', was identified by less than half of respondents. The survey identified core journals to derive the reference standard of articles, reached consensus on the use of MEDLINE as the database for which to design the filter and established support for the development of a filter. >93% respondents considered it useful or very useful.

The survey was informed by the work of Sanford *et al.* who found that even within the shared terminology of 'nursing home' there was significant international heterogeneity in the organisation and provision (Sanford *et al*., 2015). This heterogeneity extends to the range of terms used to describe the setting and this is likely to have an impact on the effectiveness of evidence synthesis, particularly if common index terms are not always used. Therefore, it is important that authors describe the care setting in primary research articles, and that those searching the literature are aware of the range of potential terms.

### *10.1.2 Part Two: Exploring current clinical practice*

The third objective of the thesis was to describe current practice around care home admission from hospital using data from a retrospective cohort study using case-note methodology enriched by the experiences and perspectives of stakeholders through qualitative case-study research.

The cohort study (n=100) found a heterogeneous picture with long hospital admissions (range 14-231 days), frequent transfers of care (31% experienced three or more transfers) and varied levels of documented assessment. Only five of the cohort had no evidence of cognitive impairment. There was a striking lack of documented patient involvement in the decision-making processes, evident in only 37% of cases, in contrast to the 92% where there was evidence of family involvement.

From 55 individuals awaiting new care home placement, only 21 were considered suitable to be approached. Of these, 11 lacked capacity to consent, two were transferred off-site, three declined to participate and five were recruited. Data were analysed on one of the datasets collected, including a patient, his nephew and three members of the multidisciplinary team. Inductive thematic analysis identified nine major themes exploring how decisions are made to discharge individuals directly into a care home from the acute hospital setting: biography &

personality; professional role; family role; limitations in local model of care; ownership of decision; risk; realising preferences; uncertainty of care home admission process; and psychological impact of in-hospital care. The preliminary findings from analysis of a single dataset from the qualitative case-study research allowed the patient voice to emerge, alongside the professional and family narrative which dominated case-note documentation (Rhynas *et al.*, 2018).

Both of these studies provide the first in-depth analysis of practice in a Scottish teaching hospital. Although further analysis is required before drawing firm conclusions from the data, these suggest practical issues around involvement of Social Work staff in the ward-based MDT and understanding of the admissions process could be improved. This work can help to inform the development of best practice guidance for clinical staff locally.

### *10.1.3 Part Three: Harnessing routinely-collected data*

The fourth objective was to identify care home residents in routinely-collected linked health data sources and describe the feasibility of using such data to identify care home residency.

Identifying care home residents in routine data sources is challenging. Use of postcode to match addresses to known care home addresses in Fife incorrectly assigned 1,057 addresses (16.8%) as care home addresses. Keyword matching could identify care home addresses, but found that mis-spellings are prevalent in routine data which can introduce error (e.g. North mistyped as Nursing). In 18,720 admissions to NHS Fife, SMR01 coding had a sensitivity of 86.0% and positive predictive value of 85.8% in identifying care home residents on admission. At discharge the sensitivity was 87.0% and positive predictive value was 84.5%. From a sample of N=10,000 records, the CHI Institution Flag had a sensitivity of 58.6% in NHS Fife and 89.3% in NHS Tayside, with positive predictive values of 99% and 97% respectively. Users of these data should be aware of their limitations. Those identified as care home residents using the CHI Institution flag are likely to be accurate. The absence of the flag, however, cannot reliably be taken to exclude care home residency.

There have been no previous evaluations of the performance of the SMR01 coding or CHI Institution Flag in identifying care home residency. The results indicate the need for further work to establish the accuracy of the data across Scotland and improve their quality before they are used as indicators for practice (Scottish Government, 2015c).

The final objective was to explore the Scottish Care Home Census as a novel national social care data source, describing the data on care home admissions and the potential added value which could be obtained through health and social care data linkage. This project was designed and conducted in collaboration with the Scottish Government Health and Care Analysis Team.

Between 73.9-80.6% of Scottish Care homes submit data to the Census, 68.2-75.1% of those reporting long-stay admissions each year returned individual resident data. From 2013-16, of N=21,368 admissions to care homes in Scotland, 56.7% were admitted from hospital. These individuals seemed to be more dependent than those admitted from home, with 67.2% *vs* 45.8% in receipt of State-funded nursing care allowance. Those admitted from hospital have higher mortality within the Census year than those admitted from home (18.2% *vs* 11.6%). There was

significant regional variation in rates of care home admission from hospital analysed by Health Board (35.9% in Orkney to 64.7% in Lanarkshire) and also in the proportion of Local Authority-funded places provided to admissions from hospital (34.4% in Eilean Siar to 73.9% in Renfrewshire).

This analysis provides the first detailed description of admissions to care homes across Scotland, comparing those admitted from hospital with those admitted from home. There has been no previous published description of admissions or exploration of rates of admissions to care homes from hospital in Scotland. A recent retrospective cohort study in the USA found new care home admission affected 3.6% of Medicare beneficiaries within six months of discharge, but that rates varied from 0.9% to 5.9% between States (Middleton *et al.*, 2017).

## 10.2 Strengths and limitations

### *10.2.1 Strengths*

The subject of this thesis comes directly from clinical practice and represents a topic of interest to patients, families, practitioners and policymakers alike. It is presented in three parts, moving from exploration of existing knowledge, through examination of practice in a specific hospital to the development of methods and design of a study to describe practice across Scotland. The findings from Chapters Two, Three, Four and Five have resulted in six publications, with planned dissemination from Chapters Six, Eight and Nine.

Wherever practicable, research has been conducted with reference to methodological guidance and reported in accordance with published guidelines.

The mixed methods approach, in collaboration with researchers in Nursing, Social Sciences, Statistics and Informatics, has allowed the topic of new care home admission from hospital to be considered from both the population and individual perspective. Combining methodological approaches helps triangulate the findings by evaluating the scale of the issue alongside the lived experience. The work presented here is the beginning of a programme of mixed methods research in this area, with the ultimate aim of generating findings to influence policy and practice in Scotland.

### *10.2.2 Limitations*

There are limitations in the methods and analyses presented in this thesis which affect the extent to which they can be applied. These limitations are discussed in detail in each chapter, with only a summary of key issues included here.

In seeking to identify observational studies, the systematic review excluded qualitative studies reporting factors associated with care home admission from hospital and also intervention studies which may alter the likelihood of a hospitalised individual requiring care home admission.

The systematic review may have excluded additional relevant studies which looked at predictors of care home admission if they evaluated change of residency at a fixed period of follow-up (e.g. six months). It will also have excluded studies using a composite outcome of care

home admission and death. It is not uncommon in the risk prediction literature for a composite 'poor outcome' measure to be used (Edmans *et al*., 2013). However, by conflating two very different outcome measures, this approach is of limited usefulness when communicating with patients and families.

Not all relevant literature may have been identified, depending on the nomenclature used to describe the care home setting, as this was so infrequently reported.

The results are affected by the predictors examined and reported in the included studies. It is acknowledged that these are limited in scope and do not adequately consider the role of availability of social support and patient preferences, or the interactions between predisposing and enabling variables (Luppa *et al*., 2008).

The meta-analysis is based on data from only 11 of the 53 studies included in the systematic review. This is indicative of the heterogeneity of the included studies in how they measured and reported predictor variables. Only studies in acute general medical, surgical or geriatric inpatient settings were included in the meta-analysis. There was a balance to be struck in performing the meta-analysis in combining clinically-appropriate data with similar study populations, but recognising the bias created by this selectivity.

The survey of care home researchers is affected by selection bias with 48.4% of responses from The Netherlands, UK and Australia. The majority of responses are from Western countries and include terms used by those writing in English language journals. While enthusiasm for a search filter is encouraging, this may be affected by responder bias based on those completing the survey, whose response rate was only 38%.

The cohort study only includes data from a single centre and thus findings may not be generalisable across other parts of Scotland. The case-note review methodology relies on documentation by practitioners and the absence of recording cannot be taken as evidence of omissions in practice and communication. The lack of inclusion of Social Work staff documentation was not anticipated at the inception of the study, but a consequence of documentation being carried out separately from the ward-based case records. Records which were missing significant periods of documentation were excluded, as the care received could not be evaluated. This introduces the potential for bias within the sample.

The qualitative case-study design is affected by selection bias, as those without capacity could not be included in the study. The study was conducted in a single NHS Health Board area, and the context and availability of health and social care provision outside the acute hospital may differ across the country. The analysis presented here is preliminary from a single dataset. As such it is limited to presentation of inductive thematic analysis, without theory generation. This requires comparison with the other five datasets and application of the analytical frame to develop understanding and meaning.

The reference standard data of care home residency used in the analysis of accuracy of SMR01 were not verified for the entirety of the cohort. However, the reference standard had been checked and updated as part of the prior analysis and was correct in the vast majority of cases. The findings for the CHI Care Home Flag analysis are limited to NHS Fife and NHS Tayside. Given

the variation in performance seen, it cannot be assumed these are generalisable across other Health Board areas.

The standalone data from the Scottish Care Home Census do not contain a consistent unique identifier variable, necessitating analysis based on admissions and not residents. Adjustment has not been performed to account for differences in the population age, sex and deprivation structure. Not all care homes submit individual resident data, introducing the potential for bias in the analysis, particularly when comparing regions, as the proportion of homes returning data varies from 46.8% of homes in Perth & Kinross to 100% in several Local Authority areas.

## 10.3 Future directions

The work presented in this thesis has implications for current practice, but indicates the need for further research to explore care home admissions following acute hospitalisation in the UK and the wider question about pathways into care. These are now considered as: implications for practice; next research steps; arising research questions; methodological issues for research and; future impact.

### *10.3.1 Implications for health and social care practice*

Part One identifies a mismatch between the existing body of literature on predictors of care home admission from hospital and the complex factors which affect these decisions in practice. Only five possible predictors could be synthesised and these alone would fail to identify those most at risk in an inpatient ward setting as they are not specific enough. The lack of data around specific predictors in part reflects the use of health-focused datasets which do not adequately capture this complexity. This must be an important factor if clinicians are considering using routine health data alone to examine pathways into long-term care. The survey highlights that practitioners consulting the published literature to inform their practice will need to include a broad range of terminology to identify studies with a care home focus.

Part Two acts as a stimulus to discussion and enquiry about the individuals who come through our care in hospital and are newly admitted to a care home. The variations in care and management captured by the case-note review may not be the same across all hospitals and regions, but help to raise the profile of this topic and how best to support those involved. By hearing the voices of the individuals affected by the process, their families and the multidisciplinary team helps to identify areas for improvement in practice.

Part Three illustrates the complexity of using existing health and social care data, but also their potential. Hospital coding of residency through SMR01 data and primary care address registration using CHI, both fail to identify all existing care home residents and consequently to identify new admissions to care homes. It is imperative that our health care systems can identify care home residents at a population level and that hospital data can reliably identify those who are newly admitted to a care home after acute hospitalisation. This measure is of interest at a policy level, to evaluate Health and Social Care Integration. Therefore, the integrity and accuracy of the underlying data must be improved. If this was prioritised it could allow for comparisons between services nationally and be used to evaluate models of care which support the

maintenance of independence. The results from the linkage project described in Chapter Nine will provide the first national data on care home admissions across the UK and should provide an impetus for evaluating practice and reducing variation.

### *10.3.2 Next research steps*

Three of the Chapters described the methods for specific additional research:

- Chapter Four described the methodology for developing a search filter for identifying published care home research. Additional funding is needed to support the technical aspects, but the work seems feasible and would be considered useful by the research community.
- Chapter Six presents the initial analysis of a single dataset from the One Chance Study. Analysis of the other five datasets is under way. After this, all six will be analysed together, comparing and contrasting findings and applying the analytical frame. These findings will help to inform local policy and practice.
- Chapter Nine sets out three stages for analysing the Scottish Care Home Census data linked to health data sources. This will build on the findings of Chapters Eight and Nine. Data analysis has started and will explore the quality of these data and describe patterns and predictors of care home admission from hospital across Scotland.

In addition to these specific planned pieces of work, this thesis identifies the need for interdisciplinary research to explore the complex issues relating to new care home admission following acute hospitalisation, particularly for those with cognitive impairment. It has also reinforced the need for researchers, policymakers and practitioners entering and using data to work collaboratively to fully exploit the potential of linked health and social care data (Atherton *et al*., 2015).

### *10.3.3 Arising research questions*

The findings of Chapters Three and Five emphasise the need to identify the process and outcome measures which matter with respect to care home decision-making from the perspectives of individuals, families, practitioners and policymakers. Thereafter, valid and reliable ways to ascertain these measures and record them systematically must be found to help ensure that practice is evaluated using meaningful metrics.

The analysis of the CHI Care Home Flag presented in Chapter Eight supports evaluation of the performance of the flag in other Health Board areas and collaboration with ISD, the Practitioner Services Division (PSD) and the Scottish Government to improve the recording of care home residency in routine data. Quality improvement work is likely to be required within individual NHS organisations. The aim is to be able to identify existing care home residents in health and social care data sources reliably and to detect changes of residency over time, e.g. after hospital discharge. Care homes are increasingly being used for temporary stays, such as for intermediate care and respite (Joint Improvememt Team and Scottish Government, 2012, Information Services Division Scotland and NHS National Services Scotland, 2016b). Thus there is an urgent need to improve the reliability of data regarding residency status. This would allow evaluation

of care pathways and comparisons between different local care models to generate evidence from routine care.

The Scottish Care Home Census is an important and under-used social care data source. I would propose a programme of work to maximise its utility. This includes:

- Exploring how census data are recorded from the perspectives of care home staff, families and residents;
- Establishing why some homes do not submit data;
- Characterising non-returning homes, as far as practicable, to be able to describe the bias this introduces into the findings;
- Scoping of potential additional domains that would provide useful and meaningful data for use by care homes and researchers;
- Exploring resident, relative and staff views around recording more data at an individual, rather than aggregate, level so they can be linked.

This work would be enhanced by a feasibility study on expanding the range of included questions, to ensure any changes are to the potential benefit of residents and staff, without being burdensome. Exploring the data collected in the Care Inspectorate Annual Return, which is an aggregate data summary would help to identify variables of shared interest. All proposed research would be done in partnership, working with the Care Inspectorate, Scottish Government Health & Care Analysis Team, ISD Care Homes Team and care homes. Such work could potentially align with the wider UK interest in improving the participation and conduct of health services research in care homes and the development of a minimum dataset (NHS National Institute for Health Research, 2018).

Linkage of the SCHC to health data sources will help to explore the predictors of care home admission from hospital, including the role of dementia and other long-term conditions, deprivation and access to care. Linkage will also allow adjusted analysis to be performed to explore the variation in rates of admission and to describe the patterns across Scotland. Once analysis of the linked data has been completed, it is likely that a programme of interdisciplinary research to explore variation will be indicated. Fieldwork to explore sites of variation will be helpful in understanding the context. This research would involve residents, families, practitioners and policymakers to understand pathways into long-term care and how these can be optimised in Scotland. This will further explore the barriers to and facilitators of successful transitions into care homes from any setting. A realist methodological approach, considering what works, for whom and under what circumstances, is likely to be beneficial in view of the complexity of this subject area (Pawson *et al*., 2005, Wong *et al*., 2016). Realist review and evaluation have proved to be effective methodologies for use in exploring how best to deliver healthcare to older people in UK care homes (Goodman *et al*., 2016, Gordon *et al*., 2018).

### *10.3.4 Methodological issues with implications for research*

Four methodological issues are highlighted which cut across the findings of this thesis:

**Improving the quality of reporting of data in published studies.** By encouraging the reporting of all data that are collected, linking to a published protocol will help allow others to

determine the relevance of findings to their practice and improve the synthesis of research findings. Reporting findings which did not achieve statistical significance would allow their incorporation in meta-analyses. The calculation of summary effect estimates relies on inclusion of all available data, not just those where a significant result was found. There is evidence of an association between significant results and publication, with studies showing positive results more likely to be published (Dwan *et al*., 2008). Although inclusion of unpublished data will not always change the results of a review (Schmucker *et al*., 2017), transparency and quality are improved with an inclusive approach.

**Promoting the use of standardised, validated measures to assess key domains in older people** such as cognitive function, frailty, physical function and dependency in activities of daily living. The heterogeneity of instruments in use is a significant barrier to synthesising evidence around effective interventions, particularly for systematic reviews (Clarke and Williamson, 2016). It is important to recognise that not all outcome assessment instruments will be relevant in all health and care systems worldwide. The context in which assessments are conducted is important in terms of their validity and relevance to the population served. There has been a move towards developing core outcome sets, as agreed and standardised measures which should be reported for specific conditions or groups (Williamson *et al*., 2012). Both the International Consortium for Health Outcomes Measurement (ICHOM) (Institute for Strategy and Competitiveness *et al*., 2016) and the Core Outcome Measures in Effectiveness Trials (COMET) (COMET Initiative, 2011-2018) have made progress in developing agreed measures. These include outcome measures for older people (Akpan *et al*., 2018) and for those with dementia (International Consortium for Health Outcomes Measurement, 2016). These should allow for easier harmonisation between outcome measures across different health and care systems.

**Describing the components and organisation of care provided in institutional long-term care settings when reporting research studies**. Effective synthesis of the existing research literature is the first step to developing and testing new interventions and evidence from research conducted in care homes is growing (Gordon *et al*., 2012). However, the international variation in the configuration and organisation of care necessitates additional explicit description when publishing research (Sanford *et al*., 2015). This will help to facilitate sharing of good practice and translation across different care environments and models of care and understanding of the variation which exists.

**Improve the clinical coding of residency status**. This topic is likely to benefit from quality improvement approaches looking at clinical care systems and ensuring that residency at admission and discharge is recorded accurately. The current coding situation results in the relative invisibility of care home residents and this lack of robust data is problematic when evaluating interventions and service changes (Burton and Guthrie, 2018). Improving the systems-level recognition of conditions including delirium (Clegg *et al*., 2010) and frailty (Harrison *et al*., 2015) through clinical coding can help to identify the service needs of older people. The care home population deserves similar effort to direct improvement.

These four issues have the common purpose of improving clarity of reporting, transparency and accuracy when categorising individuals within health and care systems. Improving the quality

and completeness of available data is a pathway to improving research and evaluation and reducing research waste (Glasziou *et al*., 2014).

### *10.3.5 Future impact of the work presented in and arising from this thesis*

Care home research in the UK has largely been dependent on individual studies with bespoke data collection and participant recruitment (Teale *et al*., 2018, Gordon *et al*., 2014). Research has not previously focussed on the transition into care, interface with acute hospital services or wider role of care homes within the landscape of services for older people. In contrast to the UK, care home data from Europe, the USA and Canada are much more readily available and routinely collected using established international systems such as the inter-resident assessment instrument (inter-RAI) (Gray *et al*., 2008) and the Minimum Data Set (MDS) (Rahman and Applebaum, 2009). These include data on the prevalence of comorbidities, dependency, geriatric syndromes and complications in long-term care settings (Onder *et al*., 2012). The use of these tools make the collection of incidence and prevalence data more standardised and at a scale not possible in individual research studies. Such tools have been introduced into UK care homes in pilot studies (Stosz and Carpenter, 2008), but uptake has been limited.

Consent and recruitment in care homes are very challenging, particularly for residents with dementia (Goodman *et al*., 2011). Any research conducted in this setting must be able to demonstrate benefit to justify the intrusion for individuals in their home. Therefore, the data generated through more routine and systematic methods of collection are likely to be more representative as they do not rely on individual recruitment and can thus include those with and without capacity and those who lack anyone to provide consent on their behalf. Developing the routine data collected in UK care homes, such as the Scottish Care Home Census, could provide insights into the population and its care needs. Establishing a reliable and accurate method to identify residents and new admissions after hospitalisation could offer huge potential for research and quality improvement efforts to improve care and develop evidence around efficacious interventions.

Ideally, to inform evidence-based policymaking it should be possible to consider the full continuum of care and look at the relationships between social care use and care home admission. Evidence using international data suggests use of home care as a means of delaying the need for care home admission (Hazard Ratio HR 0.94, 95%CI 0.90-0.98), based on each hour of home care per week (Jorgensen *et al*., 2018). Such analysis would be possible in Scotland once the Social Care Survey and Care Home data can be linked. There is an annual data collection involving those in receipt of Hospital-based complex clinical care (HBCCC) (Scottish Government, 2017b). Linkage could allow greater understanding of the relationship between this provision, care homes and acute hospital care.

Other pertinent questions, such as the 'optimal timing' for a person with dementia to move into a care home, included in the James Lind Alliance Priority Setting Partnership for Dementia (Kelly *et al*., 2015), could be informed by improved use of care home data. This could examine patterns and trends of admission and association with length of stay, hospitalisation and mortality. Although data are unlikely to provide the evidence of 'optimal timing', they could

form part of a mixed methods approach to explore this topic. They may also have a role in evaluating the impact of any interventions developed, by generating data on trends and practice.

The ability to use routine data to identify care home residency would enhance the value of existing clinical trial datasets and cohorts. This outcome is unlikely to be captured within the primary data collection phase of clinical trials but can enhance understanding of the long-term implications of interventions. Prospective cohort studies, such as the UK Biobank (Sudlow *et al.*, 2015), could adopt the methodology and care home admission could be evaluated reliably and routinely as the cohort ages, enhancing understanding of the impact of disease, treatment and interventions on this significant outcome.

The World Health Organization's 'Ten Priorities for a Decade of Action on Health Ageing' include the need to collect accurate, current and meaningful data and to promote research that addresses the needs of older people (World Health Organization, 2017). Both of these aspirations underpin the work presented in this thesis and the planned future research.

## 10.4 Final reflections

In my research I have been motivated not just to measure experiences, but to try to understand them and use this to help bridge the gap between policy and practice. When I first chose new care home admissions from hospital as the topic for this thesis I assumed from my experience in clinical practice that it would be an area with established research findings. The lack of existing research in this area is striking. While some have argued this reflects the individual nature of each decision about care home placement, the significance of this life-changing experience and costs to the individual and wider society would suggest scope for developing evidence-based guidance of good practice. It is anticipated that this would enable and support practitioners to individualise care better, helping them appreciate the impact and significance of such decisions. Furthermore, the organisation of services, including access to post-acute care and Social Work assessments must be designed and resourced to support individuals who may require long-term care and their families. Improving the quality and accuracy of our data could help understand existing care pathways and inform work with individuals, practitioners and service providers to drive service development.

This thesis has identified challenges in defining and describing what is a care home setting, identifying care home research, identifying care home residents in routine data and in establishing who experiences new care home admission after hospitalisation. These methodological challenges were not anticipated and this thesis describes practical ways to start to address them. It has also identified novel insights into the process and experiences of care home admission following acute hospitalisation, which have been facilitated by interdisciplinary collaboration. The value of researching in this area has been affirmed by the responses from public engagement and collaboration with the Scottish Government.

This thesis has identified a rich topic for research with scope for direct public benefit. It is the start of a programme of mixed methods interdisciplinary research which aims to generate evidence-based policy in Scotland to shape the care and support provided to older people who require long-term care.

# REFERENCES

ACKROYD-STOLARZ, S., GUERNSEY, J. R., MACKINNON, N. J. & KOVACS, G. 2009. Impact of adverse events on hospital disposition in community-dwelling seniors admitted to acute care. *Healthcare Quarterly,* 12**,** 34-9.

ADAMIS, D., TRELOAR, A., MARTIN, F. & MACDONALD, A. 2006. Recovery and outcome of delirium in elderly medical inpatients. *Archives of Gerontology and Geriatrics,* 43**,** 289-298.

AFRAM, B., STEPHAN, A., VERBEEK, H., BLEIJLEVENS, M. H. C., SUHONEN, R., SUTCLIFFE, C., RAAMAT, K., CABRERA, E., SOTO, M. E., HALLBERG, I. R., MEYER, G. & HAMERS, J. P. H. 2014. Reasons for Institutionalization of People With Dementia: Informal Caregiver Reports From 8 European Countries. *Journal of the American Medical Directors Association*, 15, 108-116.

AITKEN, L. M., BURMEISTER, E., LANG, J., CHABOYER, W. & RICHMOND, T. S. 2010. Characteristics and Outcomes of Injured Older Adults After Hospital Admission. *Journal of the American Geriatrics Society,* 58**,** 442-449.

AKPAN, A., ROBERTS, C., BANDEEN-ROCHE, K., BATTY, B., BAUSEWEIN, C., BELL, D., BRAMLEY, D., BYNUM, J., CAMERON, I. D., CHEN, L. K., EKDAHL, A., FERTIG, A., GENTRY, T., HARKES, M., HASLEHURST, D., HOPE, J., HURTADO, D. R., LYNDON, H., LYNN, J., MARTIN, M., ISDEN, R., RASO, F. M., SHAIBU, S., SHAND, J., SHERRINGTON, C., SINHA, S., TURNER, G., DE VRIES, N., YI, G. J., YOUNG, J. & BANERJEE, J. 2018. Standard set of health outcome measures for older persons. *BMC Geriatrics,* 18**,** 36.

ALARCÓN, T., BÁRCENA, A., GONZÁLEZ-MONTALVO, J., PEÑALOSA, C. & SALGADO, A. 1999. Factors predictive of outcome on admission to an acute geriatric ward. *Age and Ageing,* 28**,** 429-432.

ALLIANCE: HEALTH AND SOCIAL CARE ALLIANCE SCOTLAND. 2013. Being Human: A human rights based approach to health and social care in Scotland. Available: http://www.alliance-scotland.org.uk/viewpoint/2013/05/a-human-rights-based-approach-to-health-and-social-care-in-scotland/ [Accessed 10th January 2017].

ALVAREZ-MADRAZO, S., MCTAGGART, S., NANGLE, C., NICHOLSON, E. & BENNIE, M. 2016. Data Resource Profile: The Scottish National Prescribing Information System (PIS). *International Journal of Epidemiology,* 45**,** 714-715f.

ALZHEIMER'S SOCIETY. 2011. Support. Stay. Save. Care and support of people with dementia in their own homes Available: http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=526 [Accessed 29th September 2015].

ALZHEIMER'S SOCIETY. 2013. Low expectations. Attitudes on choice, care and community for people with dementia in care homes. Available: https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1628 [Accessed 13th April 2015].

ALZHEIMER SCOTLAND. 2017. *Rights-based approach to dementia* [Online]. Available: http://www.alzscot.org/campaigning/rights_based_approach [Accessed 10th January 2017].

ARAUJO DE CARVALHO, I., EPPING-JORDAN, J., MARGRIET POT, A., KELLEY, E., TORO, N., JOTHEESWARAN, A. T. & R BEARD, J. 2017. Organizing integrated health-care services to meet older people's needs. *Bulletin of the World Health Organization*, 95, 756-763.

ARMSTRONG, C., HAMILTON, L. & SHENKIN, S. 2014. *RE: Factors Predictive of Nursing Home Admission Directly From Hospital: A Systematic Review. [Personal communication].*

ASTELL, A. J., CLARK, S. A. & HARTLEY, N. T. 2008. Predictors of discharge destination for 234 patients admitted to a combined geriatric medicine/old age psychiatry unit. *International Journal of Geriatric Psychiatry,* 23**,** 903-8.

ATHERTON, I., LYNCH, E., WILLIAMS, A. & WITHAM, M. 2015. Barriers and Solutions to Linking and Using Health and Social Care Data in Scotland. *British Journal of Social Work,* 45**,** 1614-22.

ATWAL, A. 2002. Nurses' perceptions of discharge planning in acute health care: a case study in one British teaching hospital. *Journal of Advanced Nursing,* 39**,** 450-458.

ATWAL, A. & CALDWELL, K. 2005. Do all health and social care professionals interact equally: a study of interactions in multidisciplinary teams in the United Kingdom. *Scandinavian Journal of Caring Sciences,* 19**,** 268-73.

ATWAL, A., MCINTYRE, A. & WIGGETT, C. 2012. Risks with older adults in acute care settings: UK occupational therapists' and physiotherapists' perceptions of risks associated with discharge and professional practice. *Scandinavian Journal of Caring Sciences,* 26**,** 381-93.

AUDIT COMMISSION. 2011. Joining up health and social care. Available: https://www.lgcplus.com/Journals/2011/11/30/q/v/s/Joining-Up-Health-and-Social-Care.pdf [Accessed 6th November 2015].

AUDIT SCOTLAND. 2014. Reshaping care for older people Available: http://www.audit-scotland.gov.uk/docs/central/2014/nr_140206_reshaping_care.pdf [Accessed 23rd November 2015].

BACHMANN, S., FINGER, C., HUSS, A., EGGER, M., STUCK, A. E. & CLOUGH-GORR, K. M. 2010. Inpatient rehabilitation specifically designed for geriatric patients: systematic review and meta-analysis of randomised controlled trials. *BMJ,* 340**,** c1718.

BAK, G., MIERZWINSKI-URBAN, M., FITZSIMMONS, H., MORRISON, A. & MADEN-JENKINS, M. 2009. A pragmatic critical appraisal instrument for search filters: introducing the CADTH CAI. *Health Information and Libraries Journal,* 26**,** 211-9.

BANERJEE, S., MURRAY, J., FOLEY, B., ATKINS, L., SCHNEIDER, J. & MANN, A. 2003. Predictors of institutionalisation in people with dementia. *Journal of Neurology, Neurosurgery & Psychiatry,* 74**,** 1315-1316.

BARNETT, K., MERCER, S., NORBURY, M., WATT, G., WYKE, S. & GUTHRIE, B. 2012. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *The Lancet,* 380**,** 37-43.

BARRY, S. J., DINNETT, E., KEAN, S., GAW, A. & FORD, I. 2013. Are routinely collected NHS administrative records suitable for endpoint identification in clinical trials? Evidence from the West of Scotland Coronary Prevention Study. *PLoS One,* 8**,** e75379.

BASIC, D. & SHANLEY, C. 2015. Frailty in an Older Inpatient Population: Using the Clinical Frailty Scale to Predict Patient Outcomes. *Journal of Aging & Health,* 27**,** 670-685.

BAXTER, P. & JACK, S. 2008. Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. *The Qualitative Report,* 13**,** 544-559.

BAZTÁN, J. J., GONZÁLEZ, M., MORALES, C., VÁZQUEZ, E., MORÓN, N., FORCANO, S. & RUIPÉREZ, I. 2004. [Variables associated with functional recovery and post-discharge institutionalization of elderly cared in an average stay geriatric unit]. *Revista Clinica Espanola,* 204**,** 574-82.

BEALE, S., DUFFY, S., GLANVILLE, J., LEFEBVRE, C., WRIGHT, D., MCCOOL, R., VARLEY, D., BOACHIE, C., FRASER, C., HARBOUR, J. & SMITH, L. 2014. Choosing and using methodological search filters: searchers' views. *Health Information and Libraries Journal,* 31**,** 133-47.

BECKETT, D. 2013. Boarding: impacts on patients and systems. *Journal of the Royal College of Physicians of Edinburgh,* 43**,** 46-48.

BEERENS, H. C., ZWAKHALEN, S. M., VERBEEK, H., RUWAARD, D., AMBERGEN, A. W., LEINO-KILPI, H., STEPHAN, A., ZABALEGUI, A., SOTO, M., SAKS, K., BOKBERG, C., SUTCLIFFE, C. L., HAMERS, J. P. & RIGHTTIMEPLACECARE, C. 2015. Change in quality of life of people with dementia recently admitted to long-term care facilities. *Journal of Advanced Nursing,* 71**,** 1435-47.

BEIDER, A. & MORSE, S. P. 2010. Phonetic Matching: A Better Soundex. *Association of Professional Genealogists Quarterly* [Online], 25. Available: http://stevemorse.org/phonetics/bmpm2.htm [Accessed 6th May 2017].

BÉJOT, Y., TROISGROS, O., GREMEAUX, V., LUCAS, B., JACQUIN, A., KHOUMRI, C., ABOA-EBOULÉ, C., BENAÏM, C., CASILLAS, J. M. & GIROUD, M. 2012. Poststroke disposition and associated factors in a population-based study: the Dijon Stroke Registry. *Stroke,* 43**,** 2071-7.

BELLELLI, G., NOBILI, A., ANNONI, G., MORANDI, A., DJADE, C. D., MEAGHER, D. J., MACLULLICH, A. M., DAVIS, D., MAZZONE, A., TETTAMANTI, M. & MANNUCCI, P. M. 2015. Under-detection of delirium and impact of neurocognitive deficits on in-hospital mortality among acute geriatric and medical wards. *European Journal of Internal Medicine,* 26**,** 696-704.

BELLELLI, G., MORANDI, A., DAVIS, D. H. J., MAZZOLA, P., TURCO, R., GENTILE, S., RYAN, T., CASH, H., GUERINI, F., TORPILLIESI, T., DEL SANTO, F., TRABUCCHI, M., ANNONI, G. & MACLULLICH, A. M. J. 2014. Validation of the 4AT, a new instrument for rapid delirium screening: a study in 234 hospitalised older people. *Age and Ageing,* 43**,** 496-502.

BETINI, R. S. D., HIRDES, J. P., LERO, D. S., CADELL, S., POSS, J. & HECKMAN, G. 2017. A longitudinal study looking at and beyond care recipient health as a predictor of long term care home admission. *BMC Health Services Research,* 17**,** 709.

BEYNON, R., LEEFLANG, M. M., MCDONALD, S., EISINGA, A., MITCHELL, R. L., WHITING, P. & GLANVILLE, J. M. 2013. Search strategies to identify diagnostic accuracy studies in MEDLINE and EMBASE. *Cochrane Database of Systematic Reviews***,** MR000022.

BHOPAL, R., FISCHBACHER, C., POVEY, C., CHALMERS, J., MUELLER, G., STEINER, M., BROWN, H., BREWSTER, D. H. & BANSAL, N. 2011. Cohort profile: Scottish health and ethnicity linkage study of 4.65 million people exploring ethnic variations in disease in Scotland. *International Journal of Epidemiology,* 40**,** 1168-75.

BLEIJLEVENS, M. H., STOLT, M., STEPHAN, A., ZABALEGUI, A., SAKS, K., SUTCLIFFE, C., LETHIN, C., SOTO, M. E. & ZWAKHALEN, S. M. 2015. Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study. *Journal of Advanced Nursing,* 71**,** 1378-91.

BOCKERMAN, P., JOHANSSON, E. & SAARNI, S. 2012. Institutionalisation and subjective wellbeing for old-age individuals: is life really miserable in care homes? *Ageing and Society,* 32**,** 1176-1192.

BOGAN, C., KAYE, K. S., CHOPRA, T., HAYAKAWA, K., POGUE, J. M., LEPHART, P. R., BHEEMREDDY, S., LAZAROVITCH, T., ZAIDENSTEIN, R., PEREZ, F., BONOMO, R. A. & MARCHAIM, D. 2014. Outcomes of carbapenem-resistant *Enterobacteriaceae* isolation: matched analysis. *American Journal of Infection Control,* 42**,** 612-20.

BONE, A. E., GOMES, B., ETKIND, S. N., VERNE, J., MURTAGH, F. E., EVANS, C. J. & HIGGINSON, I. J. 2018. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliative Medicine,* 32**,** 329-336.

BONNEFOY, M., AYZAC, L., INGENBLEEK, Y., KOSTKA, T., BOISSON, R. C. & BIENVENU, J. 1998. Usefulness of the prognostic inflammatory and nutritional index (PINI) in hospitalized elderly patients. *International Journal for Vitamin and Nutrition Research,* 68**,** 189-95.

BORENSTEIN, M., HEDGES, L., HIGGINS, J. & ROTHSTEIN, H. 2004. Comprehensive Meta Analysis. 3.0 ed. USA: Biostat.

BOSSUYT, P., DAVENPORT, C., DEEKS, J., HYDE, C., LEEFLANG, M. & SCHOLTEN, R. 2013. Chapter 11: Interpreting results and drawing conclusions *In:* DEEKS, J., BOSSUYT, P. & GATSONIS, C. (eds.) *Cochrane Handbook for Systematic Reviews of Diagnostic Test Accuracy. Version 0.9.* The Cochrane Collaboration.

BOURDEL-MARCHASSON, I., VINCENT, S., GERMAIN, C., SALLES, N., JENN, J., RASOAMANARIVO, E., EMERIAU, J.-P., RAINFRAY, M. & RICHARD-HARSTON, S. 2004. Delirium Symptoms and Low Dietary Intake in Older Inpatients Are Independent Predictors of Institutionalization: A 1-Year Prospective Population-Based Study. *Journal of Gerontology: Medical Sciences,* 59A**,** 350-354.

BOWES, A. & BELL, D. 2007. Free Personal Care for Older People in Scotland: Issues and Implications. *Social Policy & Society,* 6**,** 435-445.

BOWLING, A. 2005. Quantitative social science: the survey. *In:* BOWLING, A. & EBRAHIM, S. (eds.) *Handbook of Health Research Methods.* Maidenhead: Open University Press.

BOWMAN, C., WHISTLER, J. & ELLERBY, M. 2004. A national census of care home residents. *Age and Ageing,* 33**,** 561-6.

BRADSHAW, L. E., GOLDBERG, S. E., LEWIS, S. A., WHITTAMORE, K., GLADMAN, J. R., JONES, R. G. & HARWOOD, R. H. 2013. Six-month outcomes following an emergency hospital admission for older adults with co-morbid mental health problems indicate complexity of care needs. *Age and Ageing,* 42**,** 582-8.

BREMER, P., CHALLIS, D., HALLBERG, I. R., LEINO-KILPI, H., SAKS, K., VELLAS, B., ZWAKHALEN, S. M. G. & SAUERLAND, D. 2017. Informal and formal care: Substitutes or complements in care for people with dementia? Empirical evidence for 8 European countries. *Health Policy,* 121**,** 613-622.

BRETT, C. & DEARY, I. 2014. Realising health data linkage from a researcher's perspective: following up the 6-Day Sample of the Scottish Mental Survey 1947. *Longitudinal and Life Course Studies,* 5**,** 283-298.

BRINDLE, N. & HOLMES, J. 2005. Capacity and coercion: dilemmas in the discharge of older people with dementia from general hospital settings. *Age and Ageing,* 34**,** 16-20.

BRITISH GERIATRICS SOCIETY. 2011. Quest for Quality. An Inquiry into the Quality of Healthcare Support for Older People in Care Homes: A Call for Leadership, Partnership and Improvement. Available: http://www.bgs.org.uk/campaigns/carehomes/quest_quality_care_homes.pdf [Accessed 6th October 2015].

BRODERICK, M. C. & COFFEY, A. 2013. Person-centred care in nursing documentation. *International Journal of Older People Nursing,* 8**,** 309-18.

BROOKER, D. 2004. What is person-centred care in dementia? *Reviews in Clinical Gerontology,* 13**,** 215-222.

BROSSEAU, L., POTVIN, L., PHILIPPE, P. & BOULANGER, Y. L. 1996. Post-stroke inpatient rehabilitation. II. Predicting discharge disposition. *American Journal of Physical Medicine & Rehabilitation,* 75**,** 431-6.

BROWN, L., CAMPBELL-JACK, D., GRAY, L., HOVALD, P., KIRKPATRICK, G., KNUDSEN, L., LEYLAND, A., MONTAGU, I. & ROSE, J. 2016. The Scottish Health Survey 2015 edition. Volume 1. Available: http://www.gov.scot/Resource/0050/00505798.pdf [Accessed 5th April 2017].

BROWN, S. H., FLINT, K., STOREY, A. & ABDELHAFIZ, A. H. 2012. Routinely assessed biochemical markers tested on admission as predictors of adverse outcomes in hospitalized elderly patients. *Hospital Practice,* 40**,** 193-201.

BRYMAN, A. 2016a. Ethnography and participant observation. *Social Research Methods.* 5th ed. Oxford: Oxford University Press.

BRYMAN, A. 2016b. Sampling in qualitative research. *Social Research Methods.* Oxford: Oxford University Press.

BUHR, G. T., KUCHIBHATLA, M. & CLIPP, E. C. 2006. Caregivers' reasons for nursing home placement: clues for improving discussions with families prior to the transition. *The Gerontologist,* 46**,** 52-61.

BURNS, E. M., RIGBY, E., MAMIDANNA, R., BOTTLE, A., AYLIN, P., ZIPRIN, P. & FAIZ, O. D. 2012. Systematic review of discharge coding accuracy. *Journal of Public Health,* 34**,** 138-48.

BURTON, J. K., FERGUSON, E., BARUGH, A. J., WALESBY, K. E., MACLULLICH, A., SHENKIN, S. D. & QUINN, T. J. 2018. Predicting discharge to institutional long-term care after stroke: a systematic review & meta-analysis. *Journal of the American Geriatrics Society,* 66**,** 161-169.

BURTON, J. K. & GUTHRIE, B. 2018. Identifying who lives in a care home - a challenge to be conquered. *Age and Ageing,* Available online 16/01/18.

BURTON, J. K., QUINN, T. J., GORDON, A. L., MACLULLICH, A. M. J., REYNISH, E. L. & SHENKIN, S. D. 2017. Identifying published studies of care home research: an international survey of researchers. *Journal of Nursing Home Research,* 3**,** 99-102.

CABRÉ, M. & SERRA-PRAT, M. 2004. Determinants of admission to nursing homes in elderly inpatients. *Revista Espanola de Geriatria y Gerontologia,* 39**,** 367-70.

CAMPBELL, S. E., CAMPBELL, M. K., GRIMSHAW, J. M. & WALKER, A. E. 2001. A systematic review of discharge coding accuracy. *Journal of Public Health Medicine,* 23**,** 205-11.

CAMPBELL, S. E., SEYMOUR, D. G., PRIMROSE, W. R. & PROJECT, A. 2004. A systematic literature review of factors affecting outcome in older medical patients admitted to hospital. *Age and Ageing,* 33**,** 110-5.

CANNY, A., ROBERTSON, F., KNIGHT, P., REDPATH, A. & WITHAM, M. D. 2016. An evaluation of the psychometric properties of the Indicator of Relative Need (IoRN) instrument. *BMC Geriatrics,* 16**,** 147.

CARE INFORMATION SCOTLAND. 2017a. *Coming out of hospital: 7. Reablement* [Online]. Available: http://www.careinfoscotland.scot/topics/how-to-get-care-services/coming-out-of-hospital/reablement/ [Accessed 12th November 2017].

CARE INFORMATION SCOTLAND. 2017b. *Coming out of hospital: What is discharge planning?* [Online]. Available: http://www.careinfoscotland.scot/topics/how-to-get-care-services/coming-out-of-hospital/what-is-discharge-planning/ [Accessed 7th October 2017].

CARE INSPECTORATE. 2015. *Why your annual returns are so important* [Online]. Available: http://www.careinspectorate.com/index.php/annual-returns/why-your-annual-returns-are-so-important [Accessed 21st December 2017].

CARE QUALITY COMMISSION. 2017. *Care homes* [Online]. Available: http://www.cqc.org.uk/what-we-do/services-we-regulate/care-homes [Accessed 17th November 2017].

CARTER, P., LAURIE, G. T. & DIXON-WOODS, M. 2015. The social licence for research: why care.data ran into trouble. *Journal of Medical Ethics,* 41**,** 404-9.

CENTRE FOR SCIENCE AND TECHNOLOGY STUDIES LEIDEN UNIVERSITY. 2017. *VOSviewer* [Online]. Available: http://www.vosviewer.com/ [Accessed 15th August 2017].

CHALLIS, D., CLARKSON, P., WILLIAMSON, J., HUGHES, J., VENABLES, D., BURNS, A. & WEINBERG, A. 2004. The value of specialist clinical assessment of older people prior to entry to care homes. *Age and Ageing,* 33**,** 25-34.

CHENOWETH, L., KABLE, A. & POND, D. 2015. Research in hospital discharge procedures addresses gaps in care continuity in the community, but leaves gaping holes for people with dementia: a review of the literature. *Australasian Journal on Ageing,* 34**,** 9-14.

CHIEF SCIENTIST OFFICE & NHS SCOTLAND. 2015. Delivering Innovation through Research - Scottish Government Health and Social Care Research Strategy. Available: http://www.gov.scot/Resource/0048/00488082.pdf [Accessed 27th November 2015].

CLARK, D., ARMSTRONG, M., ALLAN, A., GRAHAM, F., CARNON, A. & ISLES, C. 2014. Imminence of death among hospital inpatients: Prevalent cohort study. *Palliative Medicine,* 28**,** 474-479.

CLARKE, M. & WILLIAMSON, P. R. 2016. Core outcome sets and systematic reviews. *Systematic Reviews,* 5**,** 11.

CLEGG, A., BATES, C., YOUNG, J., RYAN, R., NICHOLS, L., TEALE, E. A., MOHAMMED, M. A., PARRY, J. & MARSHALL, T. 2016. Development and validation of an electronic frailty index using routine primary care electronic health record data. *Age and Ageing,* 45**,** 353-60.

CLEGG, A., WESTBY, M. & YOUNG, J. B. 2010. Under-reporting of delirium in the NHS. *Age and Ageing,* 40**,** 283-286.

CLISSETT, P., POROCK, D., HARWOOD, R. H. & GLADMAN, J. R. 2014. The responses of healthcare professionals to the admission of people with cognitive impairment to acute hospital settings: an observational and interview study. *Journal of Clinical Nursing,* 23**,** 1820-9.

COCHRANE EFFECTIVE PRACTICE AND ORGANISATION OF CARE. 2017. *EPOC resources for review authors: Suggested risk of bias criteria for EPOC reviews* [Online]. Available: http://ww.epoc.cochrane.org/resources/epoc-resources-review-authors [Accessed 15th June 2017].

COCHRANE INFORMATICS & KNOWLEDGE MANAGEMENT DEPARTMENT. 2014. *Review Manager (RevMan) 5.3* [Online]. Available: http://tech.cochrane.org/revman [Accessed 20th August 2015].

COMET INITIATIVE. 2011-2018. *Core Outcome Measures in Effectiveness Trials (COMET) Initiative* [Online]. Available: http://www.comet-initiative.org/ [Accessed 25th February 2018].

CONNOLLY, M., GRIMSHAW, J., DODD, M., CAWTHORNE, J., HULME, T., EVERITT, S., TIERNEY, S. & DEATON, C. 2009. Systems and people under pressure: the discharge process in an acute hospital. *Journal of Clinical Nursing,* 18**,** 549-558.

CORSINOVI, L., BO, M., RICAUDA AIMONINO, N., MARINELLO, R., GARIGLIO, F., MARCHETTO, C., GASTALDI, L., FISSORE, L., ZANOCCHI, M. & MOLASCHI, M. 2009. Predictors of falls and hospitalization outcomes in elderly patients admitted to an acute geriatric unit. *Archives of Gerontology and Geriatrics,* 49**,** 142-5.

COSLA & SCOTTISH GOVERNMENT. 2010. Free Personal & Nursing Care: Public Information Leaflet. Available: http://www.gov.scot/Resource/Doc/305166/0095748.pdf [Accessed 30th October 2017].

COTTER, A., MEYER, J. & S, R. 1998. Humanity of bureaucracy? The transition from hospital to long-term continuing institutional care. *NT Research,* 3**,** 247-256.

COULTER, A. & COLLINS, A. 2011. Making Shared Decision-Making a Reality: No decision about me, without me. Available: https://www.kingsfund.org.uk/sites/files/kf/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf [Accessed 3rd January 2017].

COVIDENCE. 2015. *Covidence lets you create and maintain Systematic Reviews online* [Online]. Melbourne, Australia: Alfred Health. Available: www.covidence.org [Accessed 14th September 2015].

COVINSKY, K. E., JUSTICE, A. C., ROSENTHAL, G. E., PALMER, R. M. & LANDEFELD, C. S. 1997. Measuring prognosis and case mix in hospitalized elders. The importance of functional status. *Journal of General Internal Medicine,* 12**,** 203-8.

COVINSKY, K. E., PALMER, R. M., FORTINSKY, R. H., COUNSELL, S. R., STEWART, A. L., KRESEVIC, D., BURANT, C. J. & LANDEFELD, C. S. 2003. Loss of independence in activities of daily living in older adults hospitalized with medical illnesses: increased vulnerability with age. *Journal of the American Geriatrics Society,* 51**,** 451-458.

CRITICAL APPRAISAL SKILLS PROGRAMME. 2013a. *11 questions to help you make sense of case control study* [Online]. Available: http://media.wix.com/ugd/dded87_63fb65dd4e0548e2bfd0a982295f839e.pdf [Accessed 18th August 2015].

CRITICAL APPRAISAL SKILLS PROGRAMME. 2013b. *12 questions to help you make sense of cohort study* [Online]. Available: http://media.wix.com/ugd/dded87_e37a4ab637fe46a0869f9f977dacf134.pdf [Accessed 18th August 2015].

CROSS-PARTY GROUP IN THE SCOTTISH PARLIAMENT ON ALZHEIMER'S. 2009. Charter of Rights for People with Dementia and their Carers in Scotland. Available: http://www.dementiarights.org/charter-of-rights/ [Accessed 10th January 2017].

CURTIS, L. & BURNS, A. 2016. Unit Costs of Health & Social Care 2016. Available: http://www.pssru.ac.uk/project-pages/unit-costs/2016/index.php [Accessed 20th March 2017].

DAMARELL, R. A., TIEMAN, J., SLADEK, R. M. & DAVIDSON, P. M. 2011. Development of a heart failure filter for Medline: an objective approach using evidence-based clinical practice guidelines as an alternative to hand searching. *BMC Medical Research Methodology,* 11**,** 12.

DAMARELL, R. A. & TIEMAN, J. J. 2016. Searching PubMed for a broad subject area: how effective are palliative care clinicians in finding the evidence in their field? *Health Information and Libraries Journal,* 33**,** 49-60.

DAVENPORT, R. J., DENNIS, M. S. & WARLOW, C. P. 1996. The accuracy of Scottish Morbidity Record (SMR1) data for identifying hospitalised stroke patients. *Health Bulletin,* 54**,** 402-5.

DAVIES, J. M., GAO, W., SLEEMAN, K. E., LINDSEY, K., MURTAGH, F. E., TENO, J. M., DELIENS, L., WEE, B., HIGGINSON, I. J. & VERNE, J. 2016. Using routine data to improve palliative and end of life care. *BMJ Supportive & Palliative Care,* 6**,** 257-62.

DE BUYSER, S. L., PETROVIC, M., TAES, Y. E., VETRANO, D. L. & ONDER, G. 2014. A multicomponent approach to identify predictors of hospital outcomes in older in-patients: a multicentre, observational study. *PLoS One,* 9**,** e115413.

DEEKS, J., DINNES, J., D'AMICO, R., SOWDEN, A., SAKAROVITCH, C., SONG, F., PETTICREW, M. & ALTMAN, D. 2003. Evaluating non-randomised intervention studies. *Health Technology Assessment,* 7.

DEPARTMENT OF HEALTH. 2009. Intermediate Care - Halfway Home. Available: http://webarchive.nationalarchives.gov.uk/20130124050747/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@pg/documents/digitalasset/dh_103154.pdf [Accessed 6th August 2015].

DEPARTMENT OF HEALTH. 2012. National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213137/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf [Accessed 18th August 2015].

DIERCKX DE CASTERLÉ, B., GASTMANS, C., BRYON, E. & DENIER, Y. 2012. QUAGOL: a guide for qualitative data analysis. *International Journal of Nursing Studies,* 49**,** 360-71.

DILNOT, A. 2017. The burden of triumph: meeting health and social care needs. *The Lancet,* 390**,** 1630-1631.

DIXON, J. & BARDSLEY, M. 2012. Predictive risk modelling using routine data: underexploited potential to benefit patients. *Journal of Health Services Research & Policy,* 17**,** 131-2.

DIXON-WOODS, M., BAKER, R., CHARLES, K., DAWSON, J., JERZEMBEK, G., MARTIN, G., MCCARTHY, I., MCKEE, L., MINION, J., OZIERANSKI, P., WILLARS, J., WILKIE, P. & WEST, M. 2014. Culture and behaviour in the English National Health Service: overview of lessons from a large multimethod study. *BMJ Quality & Safety,* 23**,** 106-15.

DONEGAN, K., FOX, N., BLACK, N., LIVINGSTON, G., BANERJEE, S. & BURNS, A. 2017. Trends in diagnosis and treatment for people with dementia in the UK from 2005 to 2015: a longitudinal retrospective cohort study. *The Lancet Public Health,* 2**,** e149-e156.

DONNAN, P. T., BOYLE, D. I., BROOMHALL, J., HUNTER, K., MACDONALD, T. M., NEWTON, R. W. & MORRIS, A. D. 2002. Prognosis following first acute myocardial infarction in Type 2 diabetes: a comparative population study. *Diabetic Medicine,* 19**,** 448-55.

DOYLE, L., BRADY, A.-M. & BYRNE, G. 2016. An overview of mixed methods research - revisited. *Journal of Research in Nursing,* 21**,** 623-635.

DOWNS, S. & BLACK, N. 1998. The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health,* 52**,** 377-84.

DUBOIS, M. F., DUBUC, N., RAICHE, M., CARON, C. D. & HEBERT, R. 2008. Correlates of the perceived need for institutionalisation among older adults without cognitive impairment. *Gerontology,* 54**,** 244-51.

DWAN, K., ALTMAN, D. G., ARNAIZ, J. A., BLOOM, J., CHAN, A.-W., CRONIN, E., DECULLIER, E., EASTERBROOK, P. J., VON ELM, E., GAMBLE, C., GHERSI, D., IOANNIDIS, J. P. A., SIMES, J. & WILLIAMSON, P. R. 2008. Systematic Review of the Empirical Evidence of Study Publication Bias and Outcome Reporting Bias. *PLOS ONE,* 3**,** e3081.

DWAN, K., ALTMAN, D. G., CRESSWELL, L., BLUNDELL, M., GAMBLE, C. & WILLIAMSON, P. 2011. Comparison of protocols and registry entries to published reports for randomised controlled trials. *Cochrane Database of Systematic Reviews***,** Art. No.: MR000031.

EDMANS, J., BRADSHAW, L., GLADMAN, J., FRANKLIN, M., BERDUNOV, V., ELLIOTT, R. & CONROY, S. 2013. The Identification of Seniors at Risk (ISAR) score to predict clinical outcomes and health service costs in older people discharged from UK acute medical units. *Age and Ageing,* 42**,** 747-753.

EELES, E. M., HUBBARD, R. E., WHITE, S. V., O'MAHONY, M. S., SAVVA, G. M. & BAYER, A. J. 2010. Hospital use, institutionalisation and mortality associated with delirium. *Age and Ageing,* 39**,** 470-5.

EFFECTIVE PRACTICE AND ORGANISATION OF CARE (EPOC). 2013. *What study designs should be included in an EPOC review? EPOC Resources for review authors* [Online]. Oslo: Norwegian Knowledge Centre for the Health Services. Available: http://epoc.cochrane.org/epoc-specific-resources-review-authors [Accessed 17th August 2015].

EKDAHL, A. W., LINDERHOLM, M., HELLSTROM, I., ANDERSSON, L. & FRIEDRICHSEN, M. 2012. 'Are decisions about discharge of elderly hospital patients mainly about freeing blocked beds?' A qualitative observational study. *BMJ Open,* 2**,** pii:e002027.

ELLIS, G., GARDNER, M., TSIACHRISTAS, A., LANGHORNE, P., BURKE, O., HARWOOD, R. H., CONROY, S. P., KIRCHER, T., SOMME, D., SALTVEDT, I., WALD, H., O'NEILL, D., ROBINSON, D. & SHEPPERD, S. 2017. Comprehensive geriatric assessment for older adults admitted to hospital. *Cochrane Database of Systematic Reviews,* Issue 9**,** CD006211.

EMMETT, C., POOLE, M., BOND, J. & HUGHES, J. C. 2013. Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: comparing practice with legal standards. *International Journal of Law and Psychiatry,* 36**,** 73-82.

EQUATOR NETWORK 2015. *Enhancing the QUAlity and Transparency Of health Research* [Online]. Available: http://www.equator-network.org [Accessed 17th August 2015].

EQUATOR NETWORK 2016. *Selecting the appropriate reporting guideline for your article* [Online]. Available: http://www.equator-network.org/toolkits/selecting-the-appropriate-reporting-guideline/ [Accessed 29th May 2016].

ESKA, K., GRAESSEL, E., DONATH, C., SCHWARZKOPF, L., LAUTERBERG, J. & HOLLE, R. 2013. Predictors of Institutionalization of Dementia Patients in Mild and Moderate Stages: A 4-Year Prospective Analysis. *Dementia and Geriatric Cognitive Disorders Extra,* 3**,** 426-445.

ESPEJO, A., GOUDIE, F. & TURPIN, G. 1999. Hospital discharge into nursing home care: psychological reactions and contributing factors. *Aging & Mental Health,* 3**,** 69-78.

FITZGERALD, L., BAUER, M., KOCH, S. & KING, S. 2011. Hospital discharge: recommendations for performance improvement for family carers of people with dementia. *Australasian Health Review,* 35**,** 364-370.

FLEMING, J., CALLOWAY, R., PERRELS, A., FARQUHAR, M., BARCLAY, S. & BRAYNE, C. 2017. Dying comfortably in very old age with or without dementia in different care settings - a representative "older old" population study. *BMC Geriatrics,* 17**,** 222.

FLEMING, S., BLAKE, H., GLADMAN, J., HART, E., LYMBERY, M., DEWEY, M., MCCLOUGHRY, H., WALKER, M. & MILLER, P. 2004. A randomised controlled trial of a care home rehabilitation service to reduce long-term institutionalisation for elderly people. *Age and Ageing,* 33**,** 384-390.

FOLSTEIN, M., FOLSTEIN, S. & MCHUGH, P. 1975. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.

FORD, I., MURRAY, H., PACKARD, C. J., SHEPHERD, J., MACFARLANE, P. W. & COBBE, S. M. 2007. Long-term follow-up of the West of Scotland Coronary Prevention Study. *New England Journal of Medicine,* 357**,** 1477-86.

FOX, M. T., PERSAUD, M., MAIMETS, I., BROOKS, D., O'BRIEN, K. & TREGUNNO, D. 2013. Effectiveness of early discharge planning in acutely ill or injured hospitalized older adults: a systematic review and meta-analysis. *BMC Geriatrics,* 13**,** 70.

FRIEDMAN, C. & ELHADAD, N. 2014. Natural Language Processing in Health Care and Biomedicine. *In:* SHORTLIFFE, E. H. & CIMINO, J. J. (eds.) *Biomedical Informatics: Computer Applications in Health Care and Biomedicine.* London: Springer London.

GABRIELSSON-JARHULT, F. & NILSEN, P. 2016. On the threshold: older people's concerns about needs after discharge from hospital. *Scandinavian Journal of Caring Sciences,* 30**,** 135-44.

GAIR, G. & HARTERY, T. 2001. Medical dominance in multidisciplinary teamwork: a case study of discharge decision-making in a geriatric assessment unit. *Journal of Nursing Management,* 9**,** 3-11.

GAUGLER, J. E., DUVAL, S., ANDERSON, K. A. & KANE, R. L. 2007. Predicting nursing home admission in the U.S: a meta-analysis. *BMC Geriatrics,* 7**,** 13.

GAUGLER, J., YU, F., KRICHBAUM, K. & WYMAN, J. 2009. Predictors of Nursing Home Admission for Persons with Dementia. *Medical Care,* 47**,** 191-198.

GEORGE, J., LONG, S. & VINCENT, C. 2013. How can we keep patients with dementia safe in our acute hospitals? A review of challenges and solutions. *Journal of the Royal Society of Medicine,* 106**,** 355-361.

GILL, T. M., GAHBAUER, E. A., HAN, L. & ALLORE, H. G. 2015. The role of intervening hospital admissions on trajectories of disability in the last year of life: prospective cohort study of older people. *BMJ,* 350**,** h2361.

GLANVILLE, J., BAYLISS, S., BOOTH, A., DUNDAR, Y., FERNANDES, H., FLEEMAN, N. D., FOSTER, L., FRASER, C., FRY-SMITH, A., GOLDER, S., LEFEBVRE, C., MILLER, C., PAISLEY, S., PAYNE, L., PRICE, A. & WELCH, K. 2008. So many filters, so little time: the development of a search filter appraisal checklist. *Journal of the Medical Library Association,* 96**,** 356-61.

GLANVILLE, J. M., LEFEBVRE, C., MILES, J. N. & CAMOSSO-STEFINOVIC, J. 2006. How to identify randomized controlled trials in MEDLINE: ten years on. *Journal of the Medical Library Association,* 94**,** 130-6.

GLASBY, J. 2012. *Understanding Health and Social Care,* Bristol, The Policy Press.

GLASBY, J. & LITTLECHILD, R. 2004. *The Health and Social Care Divide: The experiences of older people,* Bristol, The Policy Press.

GLASBY, J., LITTLECHILD, R., LE MESURIER, N., THWAITES, R., OLIVER, D., JONES, S. & WILKINSON, I. 2016. Who knows best? Older people's contribution to understanding and preventing avoidable hospital admissions. Available: https://www.birmingham.ac.uk/Documents/college-social-sciences/social-policy/HSMC/publications/2016/who-knows-best.pdf [Accessed 12th November 2017].

GLASBY, J., LITTLECHILD, R. & PRYCE, K. 2006. All dressed up but nowhere to go? Delayed hospital discharges and older people. *Journal of Health Services Research and Policy,* 11**,** 52-8.

GLASZIOU, P., ALTMAN, D. G., BOSSUYT, P., BOUTRON, I., CLARKE, M., JULIOUS, S., MICHIE, S., MOHER, D. & WAGER, E. 2014. Reducing waste from incomplete or unusable reports of biomedical research. *The Lancet,* 383**,** 267-276.

GODDEN, S. & POLLOCK, A. 2001. The use of acute hospital services by elderly residents of nursing and residential care homes. *Health and Social Care in the Community,* 9**,** 367-374.

GODFREY, M. & TOWNSEND, J. 2009. Delayed Hospital Discharge in England and Scotland: A Comparative Study of Policy and Implementation. *Journal of Integrated Care,* 17**,** 26-36.

GOLDBERG, S. E., WHITTAMORE, K. H., HARWOOD, R. H., BRADSHAW, L. E., GLADMAN, J. R., JONES, R. G. & MEDICAL CRISES IN OLDER PEOPLE STUDY, G. 2012. The prevalence of mental health problems among older adults admitted as an emergency to a general hospital. *Age and Ageing,* 41**,** 80-6.

GONÇALVES-BRADLEY, D., ILIFFE, S., DOLL, H., BROAD, J., GLADMAN, J., LANGHORNE, P., RICHARDS, S. & SHEPPERD, S. 2017. Early discharge hospital at home. *Cochrane Database of Systematic Reviews***,** CD000356.

GOODMAN, C., BARON, N., MACHEN, I., STEVENSON, E., EVANS, C., DAVIES, S. & ILIFFE, S. 2011. Culture, consent, costs and care homes: Enabling older people with dementia to participate in research. *Aging & Mental Health,* 15**,** 475-481.

GOODMAN, C., DENING, T., GORDON, A. L., DAVIES, S. L., MEYER, J., MARTIN, F. C., GLADMAN, J. R., BOWMAN, C., VICTOR, C., HANDLEY, M., GAGE, H., ILIFFE, S. & ZUBAIR, M. 2016. Effective health care for older people living and dying in care homes: a realist review. *BMC Health Services Research,* 16**,** 269.

GORDON, A., FRANKLIN, M., BRADSHAW, L., LOGAN, P., ELLIOTT, R. & GLADMAN, J. 2014. Health status of UK care home residents: a cohort study. *Age and Ageing,* 43**,** 97-103.

GORDON, A. L., GOODMAN, C., DAVIES, S. L., DENING, T., GAGE, H., MEYER, J., SCHNEIDER, J., BELL, B., JORDAN, J., MARTIN, F. C., ILIFFE, S., BOWMAN, C., GLADMAN, J. R. F., VICTOR, C., MAYRHOFER, A., HANDLEY, M. & ZUBAIR, M. 2018. Optimal healthcare delivery to care homes in the UK: a realist evaluation of what supports effective working to improve healthcare outcomes. *Age and Ageing,* Available online 5/1/18

GORDON, A. L., LOGAN, P. A., JONES, R. G., FORRESTER-PATON, C., MAMO, J. P. & GLADMAN, J. R. 2012. A systematic mapping review of randomized controlled trials (RCTs) in care homes. *BMC Geriatrics,* 12**,** 31.

GORDON, H. S. & ROSENTHAL, G. E. 1995. Impact of marital status on outcomes in hospitalized patients. Evidence from an academic medical center. *Archives of Internal Medicine,* 155**,** 2465-71.

GRADE WORKING GROUP 2004. Grading quality of evidence and strength of recommendations. *BMJ,* 328**,** 1490.

GRAY, L. C., BERNABEI, R., BERG, K., FINNE-SOVERI, H., FRIES, B. E., HIRDES, J. P., JONSSON, P. V., MORRIS, J. N., STEEL, K. & ARINO-BLASCO, S. 2008. Standardizing assessment of elderly people in acute care: the interRAI Acute Care instrument. *Journal of the American Geriatrics Society,* 56**,** 536-41.

GREEN, I., STOW, D., MATTHEWS, F. E. & HANRATTY, B. 2017. Changes over time in the health and functioning of older people moving into care homes: analysis of data from the English Longitudinal Study of Ageing. *Age and Ageing,* 46**,** 693-696.

GREEN, J. & THOROGOOD, N. 2011a. In-depth Interviews. *Qualitative Methods for Health Research.* 2nd ed. London: SAGE Publications.

GREEN, J. & THOROGOOD, N. 2011b. *Qualitative Methods for Health Research,* London, Sage Publications Ltd.

GREEN, J., YOUNG, J., FORSTER, A., MALLINDER, K., BOGLE, S., LOWSON, K. & SMALL, N. 2005. Effects of locality based community hospital care on independence in older people needing rehabilitation: randomised controlled trial. *BMJ,* 331**,** 317-22.

GREENER, H., POOLE, M., EMMETT, C., BOND, J., LOUW, S. J. & HUGHES, J. C. 2012. Value judgements and conceptual tensions: decision-making in relation to hospital discharge for people with dementia. *Clinical Ethics,* 7**,** 166-174.

GREENHALGH, T. 1997. How to read a paper. Getting your bearings (deciding what the paper is about). *BMJ* 315**,** 243-6.

GRIFFITHS, A., KNIGHT, A., HARWOOD, R. & GLADMAN, J. 2014. Preparation to care for confused older patients in general hospitals: a study of UK health professionals. *Age and Ageing,* 43**,** 521-527.

GROVER, M., BUSBY-WHITEHEAD, J., PALMER, M. H., HEYMEN, S., PALSSON, O. S., GOODE, P. S., TURNER, M. & WHITEHEAD, W. E. 2010. Survey of geriatricians on the effect of fecal incontinence on nursing home referral. *Journal of the American Geriatrics Society,* 58**,** 1058-62.

GUYATT, G. H., OXMAN, A. D., VIST, G. E., KUNZ, R., FALCK-YTTER, Y., ALONSO-COELLO, P. & SCHÜNEMANN, H. J. 2008. GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. *BMJ,* 336**,** 924-926.

GUZMAN-CASTILLO, M., AHMADI-ABHARI, S., BANDOSZ, P., CAPEWELL, S., STEPTOE, A., SINGH-MANOUX, A., KIVIMAKI, M., SHIPLEY, M. J., BRUNNER, E. J. & O'FLAHERTY, M. 2017. Forecasted trends in disability and life expectancy in England and Wales up to 2025: a modelling study. *The Lancet Public Health,* 2**,** e307-e313.

HAGGER-JOHNSON, G. 2016. Opportunities for longitudinal data linkage in Scotland. *Scottish Medical Journal,* 61**,** 136-145.

HAJEK, A., BRETTSCHNEIDER, C., LANGE, C., POSSELT, T., WIESE, B., STEINMANN, S., WEYERER, S., WERLE, J., PENTZEK, M., FUCHS, A., STEIN, J., LUCK, T., BICKEL, H., MOSCH, E., WAGNER, M., JESSEN, F., MAIER, W., SCHERER, M., RIEDEL-HELLER, S. G. & KONIG, H. H. 2015. Longitudinal Predictors of Institutionalization in Old Age. *PLoS One,* 10**,** e0144203.

HALEY, M. N., WELLS, Y. D. & HOLLAND, A. E. 2014. Relationship between frailty and discharge outcomes in subacute care. *Australian Health Review,* 38**,** 25-9.

HANLON, P., LAWDER, R., ELDERS, A., CLARK, D., WALSH, D., WHYTE, B. & SUTTON, M. 2007. An analysis of the link between behavioural, biological and social risk factors and subsequent hospital admission in Scotland. *Journal of Public Health,* 29**,** 405-12.

HANRATTY, B., LOWSON, E., HOLMES, L., GRANDE, G., ADDINGTON-HALL, J., PAYNE, S. & SEYMOUR, J. 2012. Funding health and social services for older people - a qualitative study of care recipients in the last year of life. *Journal of the Royal Society of Medicine,* 105**,** 201-7.

HARBOUR, J., FRASER, C., LEFEBVRE, C., GLANVILLE, J., BEALE, S., BOACHIE, C., DUFFY, S., MCCOOL, R. & SMITH, L. 2014. Reporting methodological search filter performance comparisons: a literature review. *Health Information and Libraries Journal,* 31**,** 176-94.

HARRISON, J. K., CLEGG, A., CONROY, S. P. & YOUNG, J. 2015. Managing frailty as a long-term condition. *Age and Ageing,* 44**,** 732-735.

HARRISON, J. K., GARRIDO, A. G., RHYNAS, S. J., LOGAN, G., MACLULLICH, A. M. J., MACARTHUR, J. & SHENKIN, S. D. 2017a. New institutionalisation following acute hospital admission: a retrospective cohort study. *Age and Ageing,* 46**,** 238-44.

HARRISON, J. K., NOEL-STORR, A. H., DEMEYERE, N., REYNISH, E. L. & QUINN, T. J. 2016. Outcome Measures in a Decade of Dementia and Mild Cognitive Impairment Trials. *Alzheimer's Research & Therapy,* 8**,** 48.

HARRISON, J. K., REID, J., QUINN, T. J. & SHENKIN, S. D. 2017b. Using quality assessment tools to critically appraise ageing research: a guide for clinicians. *Age and Ageing,* 46**,** 359-365.

HARRISON, J. K., WALESBY, K. E., HAMILTON, L., ARMSTRONG, C., STARR, J. M., REYNISH, E. L., MACLULLICH, A. M. J., QUINN, T. J. & SHENKIN, S. D. 2017c. Predicting discharge to institutional long-term care following acute hospitalisation: a systematic review & meta-analysis. *Age and Ageing,* 46**,** 547-558.

HARRON, K. 2016. An Introduction to Data Linkage. Available: http://adrn.ac.uk/media/174200/data_linkage_katieharron_2016.pdf [Accessed 14th December 2016].

HARTLING, L., MILNE, A., HAMM, M., VANDERMEER, B., ANSARI, M., TSERTSVADZE, A. & DRYDEN, D. 2013. Testing the Newcastle Ottawa Scale showed low reliability between individual reviewers. *Journal of Clinical Epidemiology,* 66**,** 982-93.

HEALTH & SOCIAL CARE INFORMATION CENTRE. 2015. *Caldicott Guardians* [Online]. Available: http://systems.hscic.gov.uk/infogov/caldicott [Accessed 5th January 2016].

HEALTH & SOCIAL CARE INFORMATION CENTRE & ACADEMY OF MEDICAL ROYAL COLLEGES. 2013. Standards for the clinical structure and content of patient records. Available: https://www.rcplondon.ac.uk/projects/outputs/standards-clinical-structure-and-content-patient-records [Accessed 9th January 2017].

HEALTHCARE IMPROVEMENT SCOTLAND. 2012. Procedure for accessing health records during the inspection of the care for older people in acute hospitals. Available: http://www.healthcareimprovementscotland.org/our_work/inspecting_and_regulating_care/nhs_hospitals_and_services/care_of_older_people/procedures_and_tools.aspx [Accessed 11th January 2017].

HEALTHCARE IMPROVEMENT SCOTLAND. 2015. Care of older people in hospital standards. Available: http://www.healthcareimprovementscotland.org/our_work/person-centred_care/resources/opah_standards.aspx [Accessed 9th January 2017].

HEALTHCARE IMPROVEMENT SCOTLAND. 2016. Think Delirium. Improving the care for older people: Delirium toolkit. Available: http://www.healthcareimprovementscotland.org/our_work/person-centred_care/opac_improvement_programme/delirium_toolkit.aspx [Accessed 13th February 2017].

HEARST, M. 1999. Untanging Text Data Mining. *Proceedings of the 37th Annual Meeting of the Association for Computational Linguistics* Stroudsburg, PA, USA.**,** 3-10.

HICKAM, D. H., HEDRICK, S. C. & GORTON, A. 1991. Clinicians' predictions of nursing home placement for hospitalized patients. *Journal of the American Geriatrics Society,* 39**,** 176-80.

HIGGINS, J. P. T., ALTMAN, D. G., GØTZSCHE, P. C., JÜNI, P., MOHER, D., OXMAN, A. D., SAVOVIĆ, J., SCHULZ, K. F., WEEKS, L. & STERNE, J. A. C. 2011. The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ,* 343**,** d5928.

HILDEBRAND, A. M., IANSAVICHUS, A. V., HAYNES, R. B., WILCZYNSKI, N. L., MEHTA, R. L., PARIKH, C. R. & GARG, A. X. 2014. High-performance information search filters for acute kidney injury content in PubMed, Ovid Medline and Embase. *Nephrology, Dialysis & Transplantation,* 29**,** 823-32.

HILDEBRAND, A. M., IANSAVICHUS, A. V., LEE, C. W., HAYNES, R. B., WILCZYNSKI, N. L., MCKIBBON, K. A., HLADUNEWICH, M. A., CLARK, W. F., CATTRAN, D. C. & GARG, A. X. 2012. Glomerular disease search filters for Pubmed, Ovid Medline, and Embase: a development and validation study. *BMC Medical Informatics and Decision-Making,* 12**,** 49.

HOARE, K. 2004. Care home placement: can admission direct from acute hospital be justified? *Nursing Older People,* 16**,** 14-17.

HODGES, J. 2012. *Addenbrooke's Cognitive Examination - ACE-III (English Version A)* [Online]. Available: http://dementia.ie/images/uploads/site-images/ACE-III_Administration_(UK).pdf [Accessed 13th October 2015].

HODKINSON, H. M. 1972. Evaluation of a mental test score for assessment of mental impairment in the elderly. *Age and Ageing*, 1, 233-8.

HOOGERDUIJN, J. G., BUURMAN, B. M., KOREVAAR, J. C., GROBBEE, D. E., DE ROOIJ, S. E. & SCHUURMANS, M. J. 2012. The prediction of functional decline in older hospitalised patients. *Age and Ageing,* 41**,** 381-7.

HOUSLEY, G., LEWIS, S., USMAN, A., GORDON, A. & SHAW, D. 2018. Accurate identification of hospital admissions from care homes: development and validation of an automated algorithm. *Age and Ageing,* Available online 18/12/17.

HSIEH, S., SCHUBERT, S., HOON, C., MIOSHI, E. & HODGES, J. R. 2013. Validation of the Addenbrooke's Cognitive Examination III in frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, 36, 242-50.

HUBY, G., BROOK, J. H., THOMPSON, A. & TIERNEY, A. 2007. Capturing the concealed: Interprofessional practice and older patients' participation in decision-making about discharge after acute hospitalization. *Journal of Interprofessional Care,* 21**,** 55-67.

HUBY, G., STEWART, J., TIERNEY, A. & ROGERS, W. 2004. Planning older people's discharge from acute hospital care: linking risk management and patient participation in decision-making. *Health, Risk & Society,* 6**,** 115-132.

HUMPHRIES, R. 2013. Paying for social care: Beyond Dilnot. Available: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_summary/social-care-funding-paper-may13.pdf [Accessed 10th November 2017].

HUMPHRIES, R., THORLBY, R., HOLDER, H., HALL, P. & CHARLES, A. 2016. Social care for older people: Home truths. Available: https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Social_care_older_people_Kings_Fund_Sep_2016.pdf [Accessed 5th September 2016].

HUTCHINSON, A., COSTER, J., COOPER, K., MCINTOSH, A., WALTERS, S., BATH, P., PEARSON, M., YOUNG, T., RANTELL, K., CAMPBELL, M. & RATCLIFFE, J. 2010. Comparison of case note review methods for evaluating quality and safety in health care. *Health Technology Assessment,* 14.

HYDE, A., TREACY, M. P., SCOTT, P. A., BUTLER, M., DRENNAN, J., IRVING, K., BYRNE, A., MACNEELA, P. & HANRAHAN, M. 2005. Modes of rationality in nursing documentation: biology, biography and the 'voice of nursing'. *Nursing Inquiry,* 12**,** 66-77.

IANSAVICHUS, A. V., HAYNES, R. B., SHARIFF, S. Z., WEIR, M., WILCZYNSKI, N. L., MCKIBBON, A., REHMAN, F. & GARG, A. X. 2010. Optimal search filters for renal information in EMBASE. *American Journal of Kidney Diseases,* 56**,** 14-22.

IANSAVICHUS, A. V., HILDEBRAND, A. M., HAYNES, R. B., WILCZYNSKI, N. L., LEVIN, A., HEMMELGARN, B. R., TU, K., NESRALLAH, G. E., NASH, D. M. & GARG, A. X. 2015. High-performance information search filters for CKD content in PubMed, Ovid MEDLINE, and EMBASE. *American Journal of Kidney Diseases,* 65**,** 26-32.

IFEJIKA, N. L., VAHIDY, F., ARAMBURO-MALDONADO, L. A., CAI, C., SLINE, M. R., GROTTA, J. C. & SAVITZ, S. I. 2015. Acute Intravenous Tissue Plasminogen Activator Therapy does not Impact Community Discharge after Inpatient Rehabilitation. *International Journal of Neurorehabilitation,* 2**,** 183.

IJAZ, S., VERBEEK, J., MISCHKE, C. & RUOTSALAINEN, J. 2014. Inclusion of nonrandomized studies in Cochrane systematic reviews was found to be in need of improvement. *Journal of Clinical Epidemiology,* 67**,** 645-53.

ILIFFE, S., DAVIES, S. L., GORDON, A. L., SCHNEIDER, J., DENING, T., BOWMAN, C., GAGE, H., MARTIN, F. C., GLADMAN, J. R., VICTOR, C., MEYER, J. & GOODMAN, C. 2016. Provision of NHS generalist and specialist services to care homes in England: review of surveys. *Primary Health Care Research and Development,* 17**,** 122-37.

IMISON, C., CURRY, N., HOLDER, H., CASTLE-CLARKE, S., NIMMONS, D., APPLEBY, J., THORLBY, R. & LOMBARDO, S. 2017. Shifting the balance of care. Available: https://www.nuffieldtrust.org.uk/files/2017-02/shifting-the-balance-of-care-report-web-final.pdf [Accessed 1st March 2017].

IMISON, C., POTELIAKHOFF, E. & THOMPSON, J. 2012. Older people and emergency bed use - Exploring variations. Available: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/older-people-and-emergency-bed-use-aug-2012.pdf [Accessed 12th November 2017].

IMPALLOMENI, M. & STARR, J. 1995. The changing face of community and institutional care for the elderly. *Journal of Public Health Medicine,* 17**,** 171-8.

INFORMATION COMMISSIONER'S OFFICE. 2017. Big data, artificial intelligence, machine learning and data protection. Available: https://ico.org.uk/media/for-organisations/documents/2013559/big-data-ai-ml-and-data-protection.pdf [Accessed 5th April 2017].

INFORMATION SERVICES DIVISION SCOTLAND. 2012. User Experiences of the Scottish Care Home Census. Available: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Care-Homes/Census/Uses-of-SCHC.pdf [Accessed 14th November 2017].

INFORMATION SERVICES DIVISION SCOTLAND. 2016. Quality and Reliability of Care Home Census for Adults in Scotland. Available: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Care-Homes/Census/Quality-Reliability-Summary.pdf [Accessed 14th November 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2008. Measuring Long-Term Conditions in Scotland. Available: https://www.isdscotland.org/Health-Topics/Hospital-Care/Diagnoses/2008_08_14_LTC_full_report.pdf [Accessed 5th April 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2010. *What is SPARRA?* [Online]. Available: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/SPARRA/ [Accessed 15th December 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2012. Assessment of SMR01 Data 2010-2011. Available: http://www.isdscotland.org/Health-Topics/Hospital-Care/Publications/2012-05-08/Assessment-of-SMR01Data-2010-2011-ScotlandReport.pdf [Accessed 26th November 2015].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2014. A Guide to Data to Support Health & Social Care Partnerships in Joint Strategic Commissioning and Joint Strategic Needs Assessment. Available: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/docs/Guide-to-Data-to-Support-HSCPs-8Oct2014-FINAL.pdf [Accessed 22nd December 2016].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2015. Care Home Census Available: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2015-10-20/2015-10-20-CHCensus-Report.pdf? [Accessed 20th October 2015].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2016a. *Care Home Census - Scottish Statistics on Adults Resident in Care Homes, 2006-2016. Care Home Census - tables.* [Online]. Available: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2016-10-25/SCHC_mar16_tables.xls?1 [Accessed 17th April 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2016b. Care Home Census for Adults in Scotland. Available: https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2016-10-25/2016-10-25-CHCensus-Report.pdf [Accessed 25th July 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2016c. *Delayed Discharge Definitions Manual* [Online]. Available: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Delayed-Discharges/Guidelines/docs/Delayed-discharge-Data-Definitions-Recording-Manual-FINAL.pdf [Accessed 7th October 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2016d. NHS Scotland Delayed Discharges: Background information and glossary. Available: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Delayed-Discharges/Guidelines/docs/Delayed_Discharges_Background_and_Glossary.pdf?1 [Accessed 3rd October 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2017a. *Community Health Index (CHI) Number* [Online]. Available: http://www.ndc.scot.nhs.uk/Data-Dictionary/SMR-Datasets//Patient-Identification-and-Demographic-Information/Community-Health-Index-Number/ [Accessed 14th April 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2017b. *Delayed Discharges* [Online]. Available: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Delayed-Discharges/ [Accessed 3rd October 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2017c. Delayed Discharges in NHS Scotland. Available: https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2017-12-05/2017-12-05-DelayedDischarges-Annual-Report.pdf [Accessed 30th December 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2017d. *Emergency Admissions* [Online]. Available: http://www.isdscotland.org/Health-Topics/Quality-Measurement-Framework/Emergency-Admissions/ [Accessed 12th November 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2017e. *National Data Catalogue* [Online]. Available: http://www.ndc.scot.nhs.uk/index.asp [Accessed 5th April 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2017f. *National Data Catalogue: National Datasets* [Online]. Available: http://www.ndc.scot.nhs.uk/National-Datasets/ [Accessed 4th April 2017].

INFORMATION SERVICES DIVISION SCOTLAND & NHS NATIONAL SERVICES SCOTLAND. 2017g. *Summary of Codes - SMR01 (Last update 30/03/2017)* [Online]. Available: http://www.ndc.scot.nhs.uk/Data-Dictionary/SMR-Crib-Sheets/SMR01_CRIB_300317.pdf [Accessed 30th April 2017].

INOUYE, S., RUSHING, J., FOREMAN, M., PALMER, R. & POMPEI, P. 1998. Does Delirium Contribute to Poor Hospital Outcomes? A Three-Site Epidemiologic Study. *Journal of General Internal Medicine,* 13**,** 234-242.

INOUYE, S. K., STUDENSKI, S., TINETTI, M. E. & KUCHEL, G. A. 2007. Geriatric syndromes: clinical, research, and policy implications of a core geriatric concept. *Journal of the American Geriatrics Society,* 55**,** 780-91.

INSTITUTE FOR STRATEGY AND COMPETITIVENESS, THE BOSTON CONSULTING GROUP & THE KAROLINSKA INSTITUTE. 2016. *ICHOM: The International Consortium for Health Outcomes Measurement* [Online]. Available: http://www.ichom.org/ [Accessed 7th March 2016].

INTERNATIONAL CONSORTIUM FOR HEALTH OUTCOMES MEASUREMENT. 2016. *Dementia* [Online]. Available: http://www.ichom.org/medical-conditions/dementia/ [Accessed 7th March 2016].

ISAIA, G., BO, M., AIMONINO, N., ISAIA, G., MICHELIS, G., MICELI, C., BALCET, L., TIZZANI, A. & ZANOCCHI, M. 2010. Functional decline two weeks before hospitalization in an elderly population. *Aging Clinical & Experimental Research,* 22**,** 352-355.

ISSG SEARCH FILTERS RESOURCE. 2016. *What is the ISSG Search Filter Resource?* [Online]. Available: https://sites.google.com/a/york.ac.uk/issg-search-filters-resource/what-is-the-issg-search-filter-resource [Accessed 16th August 2016].

ISSG SEARCH FILTERS RESOURCE. 2017. *The InterTASC Information Specialists' Sub-Group Search Filter Resource* [Online]. Available: https://sites.google.com/a/york.ac.uk/issg-search-filters-resource/home [Accessed 18th September 2017].

JACKSON, T., GLADMAN, J., HARWOOD, R., MACLULLICH, A., SAMPSON, E., SHEEHAN, B. & DAVIS, D. 2017. Challenges and opportunities in understanding dementia and delirium in the acute hospital. *PLoS Medicine* 14**,** e1002247.

JEFFREY, D. 2016. Empathy, sympathy and compassion in healthcare: Is there a problem? Is there a difference? Does it matter? *Journal of the Royal Society of Medicine,* 109**,** 446-452.

JENKINS, M. 2004. Evaluation of methodological search filters--a review. *Health Information and Libraries Journal,* 21**,** 148-63.

JETTE, D. U., GROVER, L. & KECK, C. P. 2003. A qualitative study of clinical decision making in recommending discharge placement from the acute care setting. *Physical Therapy,* 83**,** 224-36.

JITAPUNKUL, S., PILLAY, I. & EBRAHIM, S. 1991. The abbreviated mental test: its use and validity. *Age and Ageing*, 20, 332-6.

JOHNSON, R. A. & BIBBO, J. 2014. Relocation decisions and constructing the meaning of home: a phenomenological study of the transition into a nursing home. *Journal of Aging Studies,* 30**,** 56-63.

JOINT IMPROVEMEMT TEAM. 2018. *IoRN Resources* [Online]. Available: http://www.jitscotland.org.uk/action-areas/data/iorn/iorn-resources/ [Accessed 1st February 2018].

JOINT IMPROVEMEMT TEAM & THE SCOTTISH GOVERNMENT. 2012. Maximising Recovery, Promotion Independence: An Intermediate Care Framework for Scotland. Available: http://www.gov.scot/Resource/0039/00396826.pdf [Accessed 25th February 2018].

JOINT IMPROVEMENT TEAM. 2015. Home First - Ten Actions to Transform Discharge. . Available: http://www.jitscotland.org.uk/wp-content/uploads/2015/02/Home-First-V4.pdf [Accessed 23rd November 2015].

JÓNSSON, P., NORO, A., FINNE-SOVERI, H., JENSDÓTTIR, A., LJUNGGREN, G., BUCHT, G., GRUE, E., BJÖRNSON, J., JONSÉN, E. & SCHROLL, M. 2008. Admission profile is predictive of outcome in acute hospital care. *Aging Clinical and Experimental Research,* 20**,** 533-539.

JORGENSEN, M., SIETTE, J., GEORGIOU, A., WARLAND, A. & WESTBROOK, J. 2018. Modeling the Association Between Home Care Service Use and Entry Into Residential Aged Care: A Cohort Study Using Routinely Collected Data. *Journal of the American Medical Directors Association,* 19**,** 117-121.e3.

JUPP, B. J., MALLELA, S. K., KWAN, J., ALLEN, S., SHARMA, J. C. & VASSALLO, M. 2011. Development and evaluation of the GEMS (gait, eyesight, mental state, sedation) tool as an aid to predict outcome after hospitalization. *Geriatrics & Gerontology International,* 11**,** 8-15.

JURGENS, F., CLISSETT, P., GLADMAN, J. & HARWOOD, R. 2012. Why are family carers of people with dementia dissatisfied with general hospital care? a qualitative study. *BMC Geriatrics,* 12**,** 57.

KAMMERSGAARD, L. P., JØRGENSEN, H. S., REITH, J., NAKAYAMA, H., HOUTH, J. G., WEBER, U. J., PEDERSEN, P. M. & OLSEN, T. S. 2001. Early infection and prognosis after acute stroke: the Copenhagen Stroke Study. *Journal of Stroke and Cerebrovascular Diseases,* 10**,** 217-21.

KEEN, J. & PACKWOOD, T. 1995. Qualitative Research: Case study evaluation. *BMJ,* 311**,** 444.

KELLY, S., LAFORTUNE, L., HART, N., COWAN, K., FENTON, M. & BRAYNE, C. 2015. Dementia priority setting partnership with the James Lind Alliance: using patient and public involvement and the evidence base to inform the research agenda. *Age and Ageing,* 44**,** 985-993.

KEMM, J. R., ROBINSON, J. & VERNE, J. 2010. Social care data in England: what they tell us and what they do not tell us. *Public Health,* 124**,** 265-8.

KENDRICK, S. & CLARKE, J. 1993. The Scottish Record Linkage System. *Health Bulletin,* 51**,** 72-9.

KERR, B., GORDON, J., MACDONALD, C. & STALKER, K. 2005. Effective Social Work with Older People. Available: http://www.gov.scot/Resource/Doc/47121/0020809.pdf [Accessed 4th February 2018].

KIM, S., PARK, J., LEE, Y., SEO, H.-J., SHEEN, S.-S., HAHN, S., JANG, B.-H. & SON, H.-J. 2013. Testing a tool for assessing the risk of bias for nonrandomized studies showed moderate reliability and promising validity. *Journal of Clinical Epidemiology,* 66**,** 408-14.

KINGSTON, A., WOHLAND, P., WITTENBERG, R., ROBINSON, L., BRAYNE, C., MATTHEWS, F. E. & JAGGER, C. 2017. Is late-life dependency increasing or not? A comparison of the Cognitive Function and Ageing Studies (CFAS). *The Lancet,* 390**,** 1676-1684.

KITWOOD, T. 2004. *Dementia reconsidered: the person comes first,* Berkshire, Open University Press.

KOK, R., VERBEEK, J. A., FABER, B., VAN DIJK, F. J. & HOVING, J. L. 2015. A search strategy to identify studies on the prognosis of work disability: a diagnostic test framework. *BMJ Open,* 5**,** e006315.

KOSTER, J. 2014. *PubMed PubReMiner* [Online]. Available: http://hgserver2.amc.nl/cgi-bin/miner/miner2.cgi [Accessed 15th August 2017].

KOYAMA, T., SAKO, Y., KONTA, M. & DOMEN, K. 2011. Poststroke discharge destination: functional independence and sociodemographic factors in urban Japan. *Journal of Stroke and Cerebrovascular Diseases,* 20**,** 202-7.

KOZYRSKYI, A. L., BLACK, C., CHATEAU, D. & STEINBACH, C. 2005. Discharge outcomes in seniors hospitalized for more than 30 days. *Canadian Journal on Aging,* 24 Suppl 1**,** 107-19.

KUHN, E., DU, X., MCGRATH, K., COVENEY, S., O'REGAN, N., RICHARDSON, S., TEODORCZUK, A., ALLAN, L., WILSON, D., INOUYE, S. K., MACLULLICH, A. M. J., MEAGHER, D., BRAYNE, C., TIMMONS, S. & DAVIS, D. 2014. Validation of a Consensus Method for Identifying Delirium from Hospital Records. *PLoS ONE,* 9**,** e111823.

KULUSKI, K., IM, J. & MCGEOWN, M. 2017. "It's a waiting game" a qualitative study of the experience of carers of patients who require an alternate level of care. *BMC Health Services Research,* 17**,** 318.

KUPER, H., NICHOLSON, A. & HEMINGWAY, H. 2006. Searching for observational studies: what does citation tracking add to PubMed? A case study in depression and coronary heart disease. *BMC Medical Research Methodology,* 6**,** 4.

KWAN, J. & HAND, P. 2007. Infection after acute stroke is associated with poor short-term outcome. *Acta Neuroligica Scandinavica,* 115**,** 331-8.

LAI, S. M., ALTER, M., FRIDAY, G., LAI, S. L. & SOBEL, E. 1998. Disposition after acute stroke: who is not sent home from hospital? *Neuroepidemiology,* 17**,** 21-9.

LAING & BUISSON. 2017. Laing & Buisson Care of Older People UK Market Report 2016/17. Available: http://www.payingforcare.org/care-home-fees [Accessed 30th December 2017].

LAUDICELLA, M., MARTIN, S., LI DONNI, P. & SMITH, P. C. 2017. Do Reduced Hospital Mortality Rates Lead to Increased Utilization of Inpatient Emergency Care? A Population-Based Cohort Study. *Health Services Research*.

LAUGALAND, K., AASE, K. & WARING, J. 2014. Hospital discharge of the elderly--an observational case study of functions, variability and performance-shaping factors. *BMC Health Services Research,* 14**,** 365.

LAURIE, G., AINSWORTH, J., CUNNINGHAM, J., DOBBS, C., JONES, K. H., KALRA, D., LEA, N. C. & SETHI, N. 2015. On moving targets and magic bullets: Can the UK lead the way with responsible data linkage for health research? *International Journal of Medical Informatics,* 84**,** 933-40.

LEASK, C. F., HARVEY, J. A., SKELTON, D. A. & CHASTIN, S. F. 2015. Exploring the context of sedentary behaviour in older adults (what, where, why, when and with whom). *European Review of Aging and Physical Activity,* 12**,** 4.

LEE, P., ALEXANDER, K., HAMMILL, B., PASQUALI, S. & PETERSON, E. 2001. Representation of Elderly Persons and Women in Published Randomized Trials of Acute Coronary Syndromes. *JAMA: The Journal of the American Medical Association,* 286**,** 708-713.

LEES, R., FEARON, P., HARRISON, J. K., BROOMFIELD, N. M. & QUINN, T. J. 2012. Cognitive and mood assessment in stroke research: focused review of contemporary studies. *Stroke,* 43**,** 1678-80.

LEFEBVRE, C., GLANVILLE, J., WIELAND, L. S., COLES, B. & WEIGHTMAN, A. L. 2013. Methodological developments in searching for studies for systematic reviews: past, present and future? *Systematic Reviews,* 2**,** 78.

LINDENBERG, K., NITZ, J. C., RAHMANN, A. & BEW, P. 2014. Predictors of discharge destination in a geriatric population after undergoing rehabilitation. *Journal of Geriatric Physical Therapy,* 37**,** 92-8.

LINGARD, L., ALBERT, M. & LEVINSON, W. 2008. Grounded theory, mixed methods, and action research. *BMJ,* 337**,** a567.

LIU, B., MOORE, J. E., ALMAAWIY, U., CHAN, W. H., KHAN, S., EWUSIE, J., HAMID, J. S. & STRAUS, S. E. 2018. Outcomes of Mobilisation of Vulnerable Elders in Ontario (MOVE ON): a multisite interrupted time series evaluation of an implementation intervention to increase patient mobilisation. *Age and Ageing,* 47**,** 112-119.

LIVINGSTON, G., LEAVEY, G., MANELA, M., LIVINGSTON, D., RAIT, G., SAMPSON, E., BAVISHI, S., SHAHRIYARMOLKI, K. & COOPER, C. 2010. Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *BMJ,* 341**,** c4184.

LO, C.-L., MERTZ, D. & LOEB, M. 2014. Newcastle-Ottawa Scale: comparing reviewers' to authors' assessments. *BMC Medical Research Methodology,* 14**,** 45.

LORD, K., LIVINGSTON, G. & COOPER, C. 2017. A feasibility randomised controlled trial of the DECIDE intervention: dementia carers making informed decisions. *British Journal of Psychiatry Open,* 3**,** 12-14.

LORD, K., LIVINGSTON, G., ROBERTSON, S. & COOPER, C. 2016. How people with dementia and their families decide about moving to a care home and support their needs: development of a decision aid, a qualitative study. *BMC Geriatrics,* 16**,** 68.

LOWRY, R. 2017. *VassarStats: Website for Statistical Computation* [Online]. Available: http://vassarstats.net/ [Accessed 18th July 2017].

LOWSON, E., HANRATTY, B., HOLMES, L., ADDINGTON-HALL, J., GRANDE, G., PAYNE, S. & SEYMOUR, J. 2013. From 'conductor' to 'second fiddle': older adult care recipients' perspectives on transitions in family caring at hospital admission. *International Journal of Nursing Studies,* 50**,** 1197-205.

LUCK, T., LUPPA, M., WEBER, S., MATSCHINGER, H., GLAESMER, H., KONIG, H.-H., ANGERMEYER, M. C. & RIEDEL-HELLER, S. G. 2008. Time until Institutionalization in Incident Dementia Cases - Results of the Leipzig Longitudinal Study of the Aged (LEILA 75+). *Neuroepidemiology,* 31**,** 100-108.

LUK, J., CHIU, P. & CHU, L. 2009. Factors affecting institutionalization in older Hong Kong Chinese patients after recovery from acute medical illnesses. *Archives of Gerontology and Geriatrics,* 49**,** e110-e114.

LUPPA, M., LUCK, T., BRAHLER, E., KONIG, H.-H. & RIEDEL-HELLER, S. G. 2008. Prediction of Institutionalisation in Dementia. A systematic review. *Dementia and Geriatric Cognitive Disorders,* 26**,** 65-78.

LUPPA, M., LUCK, T., WEYERER, S., KONIG, H. H., BRAHLER, E. & RIEDEL-HELLER, S. G. 2010. Prediction of institutionalization in the elderly. A systematic review. *Age and Ageing,* 39**,** 31-38.

LUPPA, M., LUCK, T., WEYERER, S., KONIG, H. H. & RIEDEL-HELLER, S. G. 2009. Gender differences in predictors of nursing home placement in the elderly: a systematic review. *International Psychogeriatrics,* 21**,** 1015-25.

LUPPA, M., RIEDEL-HELLER, S., STEIN, J., LEICHT, H., KONIG, H.-H., VAN DEN BUSSCHE, H., MAIER, W., SCHERER, M., BICKEL, H., MOSCH, E., WERLE, J., PENTZEK, M., FUCHS, A., EISELE, M., JESSEN, F., TEBARTH, F., WIESE, B., WEYERER, S. & GROUP, F. T. A. S. 2012. Predictors of Institutionalisation in Incident Dementia - Results of the German Study on Ageing, Cognition and Dementia in Primary Care Patients (AgeCoDe Study). *Dementia and Geriatric Cognitive Disorders,* 33**,** 282-288.

MACKAY, D., HAW, S., AYRES, J. G., FISCHBACHER, C. & PELL, J. P. 2010. Smoke-free legislation and hospitalizations for childhood asthma. *New England Journal of Medicine,* 363**,** 1139-45.

MARENGONI, A., AGUERO-TORRES, H., TIMPINI, A., COSSI, S. & FRATIGLIONI, L. 2008. Rehabilitation and Nursing Home Admission after Hospitalization in Acute Geriatric Patients. *Journal of the American Medical Directors Association,* 9**,** 265-270.

MARGULIS, A. V., PLADEVALL, M., RIERA-GUARDIA, N., VARAS-LORENZO, C., HAZELL, L., BERKMAN, N. D., VISWANATHAN, M. & PEREZ-GUTTHANN, S. 2014. Quality assessment of observational studies in a drug-safety systematic review, comparison of two tools: the Newcastle-Ottawa Scale and the RTI item bank. *Clinical Epidemiology,* 6**,** 359-68.

MATTHEWS, F. E., BENNETT, H., WITTENBERG, R., JAGGER, C., DENING, T. & BRAYNE, C. 2016. Who Lives Where and Does It Matter? Changes in the Health Profiles of Older People Living in Long Term Care and the Community over Two Decades in a High Income Country. *PLoS One,* 11**,** e0161705.

MAYNE, D., ALLAN, L., REYNISH, E., MACLULLICH, A. & VARDY, E. 2014. Experience and opinions on post-graduate dementia training in the UK: a survey of selected consultant geriatricians. *Age and Ageing,* 43**,** 263-266.

MCCANN, M., DONNELLY, M. & O'REILLY, D. 2011. Living arrangements, relationship to people in the household and admission to care homes for older people. *Age and Ageing,* 40**,** 358-63.

MCCANN, M., GRUNDY, E. & O'REILLY, D. 2012. Why is housing tenure associated with a lower risk of admission to a nursing or residential home? Wealth, health and the incentive to keep 'my home'. *Journal of Epidemiology and Community Health,* 66**,** 166-9.

MCKIBBON, K. A., LOKKER, C., WILCZYNSKI, N. L., HAYNES, R. B., CILISKA, D., DOBBINS, M., DAVIS, D. A. & STRAUS, S. E. 2012. Search filters can find some but not all knowledge translation articles in MEDLINE: an analytic survey. *Journal of Clinical Epidemiology,* 65**,** 651-9.

MCKINSTRY, B., SULLIVAN, F. M., VASISHTA, S., ARMSTRONG, R., HANLEY, J., HAUGHNEY, J., PHILIP, S., SMITH, B. H., WOOD, A. & PALMER, C. N. 2017. Cohort profile: the Scottish Research register SHARE. A register of people interested in research participation linked to NHS data sets. *BMJ Open,* 7**,** e013351.

MCMANUS, J., PATHANSALI, R., HASSAN, H., OULDRED, E., COOPER, D., STEWART, R., MACDONALD, A. & JACKSON, S. 2009. The course of delirium in acute stroke. *Age and Ageing,* 38**,** 385-9.

MCMASTER UNIVERSITY AND EVIDENCE PRIME INC. 2015. *GRADEpro Guideline Development Tool* [Online]. Available: http://www.guidelinedevelopment.org/ [Accessed 20th August 2015].

MCMASTER UNIVERSITY & HEALTH INFORMATION RESEARCH UNIT. 2016. *Search Filters for MEDLINE in Ovid Syntax and the PubMed translation* [Online]. Available: https://hiru.mcmaster.ca/hiru/HIRU_Hedges_MEDLINE_Strategies.aspx [Accessed 18th September 2017].

MCMURDO, M. E., ROBERTS, H., PARKER, S., WYATT, N., MAY, H., GOODMAN, C., JACKSON, S., GLADMAN, J., O'MAHONY, S., ALI, K., DICKINSON, E., EDISON, P. & DYER, C. 2011. Improving recruitment of older people to research through good practice. *Age and Ageing,* 40**,** 659-65.

MCMURDO, M. E. T. & WITHAM, M. D. 2013. Unnecessary ward moves. *Age and Ageing,* 42**,** 555-556.

MEDFORD, A. 2013. Aberrant clinical coding: an underappreciated entity for NHS Trusts, clinicians and coders. *Journal of the Royal College of Physicians of Edinburgh,* 43**,** 101-102.

MIDDLETON, A., LI, S., KUO, Y. F., OTTENBACHER, K. J. & GOODWIN, J. S. 2018. New Institutionalization in Long-Term Care After Hospital Discharge to Skilled Nursing Facility. *Journal of the American Geriatrics Society,* 66**,** 56-63.

MIDDLETON, A., ZHOU, J., OTTENBACHER, K. J. & GOODWIN, J. S. 2017. Hospital Variation in Rates of New Institutionalizations Within 6 Months of Discharge. *Journal of the American Geriatrics Society,* 65**,** 1206-1213.

MINNEY, M. J. & RANZIJN, R. 2016. "We Had a Beautiful Home . . . But I Think I'm Happier Here": A Good or Better Life in Residential Aged Care. *The Gerontologist,* 56**,** 919-27.

MITTELMAN, M., HALEY, W., CLAY, O. & ROTH, D. 2006. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology,* 67**,** 1592-1599.

MOHER, D., LIBERATI, A., TETZLAFF, J., DG, A. & GROUP, T. P. 2009. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Medicine,* 6**,** e1000097.

MOORE, D. C. & HANRATTY, B. 2013. Out of sight, out of mind? a review of data available on the health of care home residents in longitudinal and nationally representative cross-sectional studies in the UK and Ireland. *Age and Ageing,* 42**,** 798-803.

MORANDI, A., DAVIS, D., TAYLOR, J. K., BELLELLI, G., OLOFSSON, B., KREISEL, S., TEODORCZUK, A., KAMHOLZ, B., HASEMANN, W., YOUNG, J., AGAR, M., DE ROOIJ, S. E., MEAGHER, D., TRABUCCHI, M. & MACLULLICH, A. M. 2013. Consensus and variations in opinions on delirium care: a survey of European delirium specialists. *International Psychogeriatrics,* 25**,** 2067-75.

MORRIS, A. D., BOYLE, D. I., MACALPINE, R., EMSLIE-SMITH, A., JUNG, R. T., NEWTON, R. W. & MACDONALD, T. M. 1997. The diabetes audit and research in Tayside Scotland (DARTS) study: electronic record linkage to create a diabetes register. DARTS/MEMO Collaboration. *BMJ,* 315**,** 524-8.

MURDOCH, T. & DETSKY, A. 2013. The Inevitable Application of Big Data to Health Care. *JAMA: The Journal of the American Medical Association,* 309**,** 1351-2.

MURIE-FERNÁNDEZ, M., ORTEGA-CUBERO, S., CARMONA-ABELLÁN, M., MEYER, M. & TEASELL, R. 2012. ["Time is brain": only in the acute phase of stroke?]. *Neurologia*, 27, 197-201.

MURRAY, G. R., CAMERON, I. D. & CUMMING, R. G. 2007. The consequences of falls in acute and subacute hospitals in Australia that cause proximal femoral fractures. *Journal of the American Geriatrics Society*, 55, 577-82.

MURTHY, V. H., KRUMHOLZ, H. M. & GROSS, C. P. 2004. Participation in cancer clinical trials: race-, sex-, and age-based disparities. *JAMA: The Journal of the American Medical Association,* 291**,** 2720-6.

MUSTAFA, F., GILLIGAN, P., OBU, D., O'KELLY, P., O'HEA, E., LLOYD, C., KELADA, S., HEFFERNAN, A. & HOULIHAN, P. 2016. 'Delayed discharges and boarders': a 2-year study of the relationship between patients experiencing delayed discharges from an acute hospital and boarding of admitted patients in a crowded ED. *Emergency Medical Journal,* 33**,** 636-40.

NADKARNI, P. M., OHNO-MACHADO, L. & CHAPMAN, W. W. 2011. Natural language processing: an introduction. *Journal of the American Medical Informatics Association,* 18**,** 544-551.

NARDI, R., SCANELLI, G., TRAGNONE, A., LOLLI, A., KALFUS, P., BALDINI, A., GHEDINI, T., BOMBARDA, S., FIADINO, L. & DI CIOMMO, S. 2007. Difficult hospital discharges in internal medicine wards. *Internal and Emergency Medicine,* 2**,** 95-9.

NATIONAL AUDIT OFFICE. 2016. Discharging older patients from hospital. Available: https://www.nao.org.uk/report/discharging-older-patients-from-hospital/ [Accessed 30th September 2016].

NATIONAL AUDIT OFFICE. 2017. Health and social care integration. Available: https://www.nao.org.uk/wp-content/uploads/2017/02/Health-and-social-care-integration-Summary.pdf [Accessed 7th October 2017].

NATIONAL DATA GUARDIAN FOR HEALTH AND CARE. 2016. Review of Data Security, Consent and Opt-Outs. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/535024/data-security-review.PDF [Accessed 11th July 2016].

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE. 2015a. Transition between inpatient hospital settings and community of care home settings for adults with social care needs (NG 27). Available: http://nice.org.uk/guidance/ng27 [Accessed 8th December 2015].

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE. 2015b. Transition between inpatient hospital settings and community or care home settings for adults with social care needs: Full version. Available: https://www.nice.org.uk/guidance/ng27/evidence/full-guideline-pdf-2185185565 [Accessed 7th October 2017].

NATIONAL RECORDS OF SCOTLAND. 2017a. *About the Scottish Longitudinal Survey (SLS)* [Online]. Available: https://www.nrscotland.gov.uk/statistics-and-data/scottish-longitudinal-study-sls/about-sls [Accessed 5th April 2017].

NATIONAL RECORDS OF SCOTLAND. 2017b. *Mid-Year Population Estimates Scotland, Mid-2016* [Online]. Edinburgh: National Statistics. Available: https://www.nrscotland.gov.uk/files//statistics/population-estimates/mid-year-2016/16mype-cahb.pdf [Accessed 25th July 2017].

NATIONAL RECORDS OF SCOTLAND. 2017c. *Scotland's census* [Online]. Available: https://www.nrscotland.gov.uk/statistics-and-data/census [Accessed 5th April 2017].

NATIONAL VOICES & NHS ENGLAND. 2013. A narrative for person-centred co-ordinated care. Available: https://www.nationalvoices.org.uk/sites/default/files/public/publications/narrative-for-person-centred-coordinated-care.pdf [Accessed 7th October 2017].

NEUHAUS, V., BOT, A. G., SWELLENGREBEL, C. H., JAIN, N. B., WARNER, J. J. & RING, D. C. 2014. Treatment choice affects inpatient adverse events and mortality in older aged inpatients with an isolated fracture of the proximal humerus. *Journal of Shoulder and Elbow Surgery,* 23**,** 800-6.

NHS BENCHMARKING NETWORK. 2015. National Audit of Intermediate Care Summary Report Available: http://www.nhsbenchmarking.nhs.uk/partnership-projects/National-Audit-of-Intermediate-Care/year-four.php [Accessed 10th November 2017].

NHS CHOICES. 2014. *Permanent admissions of older people (aged 65 and over) to residential and nursing care homes, per 100,000 population* [Online]. Available: http://www.nhs.uk/Scorecard/Pages/IndicatorFacts.aspx?MetricId=8068 [Accessed 7th October 2017].

NHS ENGLAND. 2014. Safe, compassionate care for frail older people using an integrated care pathway: Practical guidance for commissioners, providers and nursing, medical and allied health professional leaders. . Available: https://www.england.nhs.uk/wp-content/uploads/2014/02/safe-comp-care.pdf [Accessed 16th October 2015].

NHS ENGLAND. 2017. Delayed Transfers of Care Statistics for England 2016/17. Available: https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2013/04/2016-17-Delayed-Transfers-of-Care-Annual-Report.pdf [Accessed 4th October 2017].

NHS HEALTH SCOTLAND. 2016. Human rights and the right to health. Available: http://www.healthscotland.scot/publications/human-rights-and-the-right-to-health [Accessed 9th January 2017].

NHS NATIONAL INSTITUTE FOR HEALTH RESEARCH. 2015. *Journal Library: HS&DR - 13/54/55: Understanding the outcomes of people with cognitive impairment and/or dementia admitted to the general hospital* [Online]. Available: https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/135455/#/ [Accessed 15th February 2018].

NHS NATIONAL INSTITUTE FOR HEALTH RESEARCH. 2018. *Researcher-led Specification document: 18/11 Improving the participation and conduct of health services research in nursing and care homes at scale* [Online]. Available: https://www.nihr.ac.uk/funding-and-support/documents/current-funding-opportunities/hsdr/18-11-spec-doc.pdf [Accessed 19th February 2018].

NHS NATIONAL SERVICES SCOTLAND. 2016a. *Public Benefit and Privacy Panel for Health & Social Care* [Online]. Available: http://www.informationgovernance.scot.nhs.uk/pbpphsc/ [Accessed 14th April 2017].

NHS NATIONAL SERVICES SCOTLAND. 2016b. The changing functional needs and dependency of people living in care homes. Available: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2017-02-28/2017-02-28-The-changing-functional-needs-and-dependency-of-people-living-in-care-homes-Report.pdf [Accessed 1st March 2017].

NHS NATIONAL SERVICES SCOTLAND & SCOTTISH GOVERNMENT. 2016. *Scottish Primary Care Information Resource (SPIRE) Health Professionals* [Online]. Available: http://spire.scot/professional/ [Accessed 29th May 2017].

NHS SCOTLAND. 2015. Chief Medical Officer's Annual Report 2014-15: REALISTIC MEDICINE. Available: http://www.gov.scot/Resource/0049/00492520.pdf [Accessed 28th January 2016].

NHS SCOTLAND & SCOTTISH GOVERNMENT HEALTH DELIVERY DIRECTORATE IMPROVEMENT AND SUPPORT TEAM. 2010. Anticipatory Care Planning: Frequently Asked Questions. Available: http://www.gov.scot/Resource/Doc/309277/0097422.pdf [Accessed 3rd January 2017].

NIH US NATIONAL LIBRARY OF MEDICINE. 2016. *MeSH on Demand* [Online]. Available: https://meshb.nlm.nih.gov/MeSHonDemand [Accessed 15th August 2017].

NORRIS, S. L., MOHER, D., REEVES, B. C., SHEA, B., LOKE, Y., GARNER, S., ANDERSON, L., TUGWELL, P. & WELLS, G. 2013. Issues relating to selective reporting when including non-randomized studies in systematic reviews on the effects of healthcare interventions. *Research Synthesis Methods,* 4**,** 36-47.

NOSBUSCH, J. M., WEISS, M. E. & BOBAY, K. L. 2011. An integrated review of the literature on challenges confronting the acute care staff nurse in discharge planning. *Journal of Clinical Nursing,* 20**,** 754-774.

NUFFIELD COUNCIL ON BIOETHICS. 2015. The collection, linking and use of data in biomedical research and health care: ethical issues. Available: http://nuffieldbioethics.org/wp-content/uploads/Biological_and_health_data_web.pdf [Accessed 27th November 2015].

NUOTIO, M., TAMMELA, T. L., LUUKKAALA, T. & JYLHA, M. 2003. Predictors of institutionalization in an older population during a 13-year period: the effect of urge incontinence. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences,* 58**,** 756-62.

O'CATHAIN, A., MURPHY, E. & NICHOLL, J. 2010. Three techniques for integrating data in mixed methods studies. *BMJ,* 341**,** c4587.

OFFICE FOR NATIONAL STATISTICS. 2010. United Kingdom Health Statistics 2010. Available: http://www.ons.gov.uk/ons/rel/ukhs/united-kingdom-health-statistics/2010/index.html [Accessed 29th September 2015].

OFFICE FOR NATIONAL STATISTICS. 2015. *How has life expectancy changed over time?* [Online]. Available: https://visual.ons.gov.uk/how-has-life-expectancy-changed-over-time/ [Accessed 14th November 2017].

OFFICE FOR NATIONAL STATISTICS. 2017. *Population estimates for UK, England and Wales, Scotland and Northern Ireland: mid-2016* [Online]. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/latest [Accessed 30th December 2017].

OFFICE OF THE PUBLIC GUARDIAN (SCOTLAND). 2017a. *The PoA document* [Online]. Available: http://www.publicguardian-scotland.gov.uk/power-of-attorney/power-of-attorney/the-power-of-attorney-document [Accessed 13th February 2017].

OFFICE OF THE PUBLIC GUARDIAN (SCOTLAND). 2017b. *What is the incapacity statement?* [Online]. Available: http://www.publicguardian-scotland.gov.uk/power-of-attorney/power-of-attorney/the-incapacity-statement [Accessed 13th February 2017].

OFFORD, N., HARRIMAN, P. & DOWNES, P. 2017. Discharge to assess: transforming the discharge process of frail older patients. *Future Hospital Journal,* 4**,** 30-32.

OLIVER, D., FOOT, C. & HUMPHRIES, R. 2014. Making our health and care systems fit for an ageing population. Available: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/making-health-care-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf [Accessed 10th December 2015].

O'MARA-EVES, A., THOMAS, J., MCNAUGHT, J., MIWA, M. & ANANIADOU, S. 2015. Using text mining for study identification in systematic reviews: a systematic review of current approaches. *Systematic Reviews,* 4**,** 5.

ONDER, G., CARPENTER, I., FINNE-SOVERI, H., GINDIN, J., FRIJTERS, D., HENRARD, J. C., NIKOLAUS, T., TOPINKOVA, E., TOSATO, M., LIPEROTI, R., LANDI, F. & BERNABEI, R. 2012. Assessment of nursing home residents in Europe: the Services and Health for Elderly in Long TERm care (SHELTER) study. *BMC Health Services Research,* 12**,** 5.

ORDNANCE SURVEY & SCOTTISH GOVERNMENT GEOGRAPHIC INFORMATION SCIENCE & ANALYSIS TEAM 2015. Health and Social Care Integration Partnerships.

ORDNANCE SURVEY & SCOTTISH GOVERNMENT GEOGRAPHIC INFORMATION SCIENCE & ANALYSIS TEAM 2016. Location of care homes in 2015.

PANELLA, L., LA PORTA, F., CASELLI, S., MARCHISIO, S. & TENNANT, A. 2012. Predicting the need for institutional care shortly after admission to rehabilitation: Rasch analysis and predictive validity of the BRASS Index. *European Journal of Physical and Rehabilitation Medicine,* 48**,** 443-54.

PARTRIDGE, J., COLLINGRIDGE, G., GORDON, A., MARTIN, F., HARARI, D. & DHESI, J. 2014. Where are we in perioperative medicine for older surgical patients? A UK survey of geriatric medicine delivered services in surgery. *Age and Ageing,* 43**,** 721-724.

PAUTEX, S., JACQUES, M. C., SANT, A., HERRMANN, F. & CHEVALLEY, T. 2005. A short comprehensive assessment to predict outcome of elderly patients after hip fracture. *Aging Clinical & Experimental Research,* 17**,** 116-20.

PAVIS, S. & MORRIS, A. 2015. Unleashing the power of administrative health data: the Scottish model. *Public Health Research & Practice,* 25**,** e2541541.

PAWSON, R., GREENHALGH, T., HARVEY, G. & WALSHE, K. 2005. Realist review--a new method of systematic review designed for complex policy interventions. *Journal of Health Services Research & Policy,* 10 Suppl 1**,** 21-34.

PHILP, I. 2015. The contribution of geriatric medicine to integrated care for older people. *Age and Ageing,* 44**,** 11-5.

PHILP, I., MILLS, K. A., THANVI, B., GHOSH, K. & LONG, J. F. 2013. Reducing hospital bed use by frail older people: results from a systematic review of the literature. *International Journal of Integrated Care,* 13**,** e048.

PINEDO, S., ERAZO, P., TEJADA, P., LIZARRAGA, N., AYCART, J., MIRANDA, M., ZALDIBAR, B., GAMIO, A., GÓMEZ, I., SANMARTIN, V. & BILBAO, A. 2014. Rehabilitation efficiency and destination on discharge after stroke. *European Journal of Physical and Rehabilitation Medicine,* 50**,** 323-33.

POOLE, M., BOND, J., EMMETT, C., GREENER, H., LOUW, S. J., ROBINSON, L. & HUGHES, J. C. 2014. Going home? An ethnographic study of assessment of capacity and best interests in people with dementia being discharged from hospital. *BMC Geriatrics,* 14**,** 56.

PORTELLI, R., LOWE, D., IRWIN, P., PEARSON, M. & RUDD, A. G. 2005. Institutionalization after stroke. *Clinical Rehabilitation,* 19**,** 97-108.

QUINN, T., MCCOWAN, C. & STOTT, D. J. 2017. Is statin use associated with care-home admission: describing care-home admission as a novel study "outcome" using long term follow up of trial participants and screenees. Chief Scientist Office HICG/1/14.

RAHMAN, A. N. & APPLEBAUM, R. A. 2009. The nursing home Minimum Data Set assessment instrument: manifest functions and unintended consequences--past, present, and future. *The Gerontologist,* 49**,** 727-35.

RAMIREZ-MORENO, J. M., FALCÓN, A., LUENGO-ÁLVAREZ, J., MOHEDANO, J., GÓMEZ-GUTIÉRREZ, M., CABALLERO, M., OJALVO HOLGADO, M. J., PORTILLA, J. C., ALONSO-RUIZ, M., SERRANO, A., TENA-MORA, D. & CASADO-NARANJO, I. 2008. [Stroke in the very old. Care in neurology units versus others general medical ward]. *Neurologia,* 23**,** 288-93.

RAZA, Z., HOLDSWORTH, R. J. & MCCOLLUM, P. T. 1999. Accuracy of the recording of operative events by the Scottish Morbidity Record 1 (SMR1) for a teaching hospital vascular unit. *Journal of the Royal College of Surgeons of Edinburgh,* 44**,** 96-8.

REED, J. & MORGAN, D. 1999. Discharging older people from hospital to care homes: implications for nursing. *Journal of Advanced Nursing,* 29**,** 819-25.

REEVES, B. C., DEEKS, J. J., HIGGINS, J., WELLS, G. A. & ON BEHALF OF THE COCHRANE NON-RANDOMISED STUDIES METHODS GROUP 2011. Chapter 13: Including non-randomized studies. *In:* HIGGINS, J. & GREEN, S. (eds.) *Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 (updated March 2011).* The Cochrane Collaboration. Available: http://handbook.cochrane.org [Accessed 24th October 2016].

REEVES, B. C., HIGGINS, J. P., RAMSAY, C., SHEA, B., TUGWELL, P. & WELLS, G. A. 2013. An introduction to methodological issues when including non-randomised studies in systematic reviews on the effects of interventions. *Research Synthesis Methods,* 4**,** 1-11.

REEVES, S., KUPER, A. & HODGES, B. D. 2008. Qualitative research methodologies: ethnography. *BMJ,* 337.

RELEVO, R. 2012. Chapter 4: effective search strategies for systematic reviews of medical tests. *Journal of General Internal Medicine,* 27 Suppl 1**,** S28-32.

REYNISH, E. L., HAPCA, S. M., DE SOUZA, N., CVORO, V., DONNAN, P. T. & GUTHRIE, B. 2017. Epidemiology and outcomes of people with dementia, delirium, and unspecified cognitive impairment in the general hospital: prospective cohort study of 10,014 admissions. *BMC Medicine,* 15**,** 140.

RHYNAS, S. J., GARRIDO, A. G., BURTON, J. K., LOGAN, G. & MACARTHUR, J. 2018. New care home admission following hospitalisation: how do older people, families and professionals make decisions about discharge destination? A case-study narrative analysis. *International Journal of Older People Nursing,* Available online 24/03/18.

RIBBE, M. W., LJUNGGREN, G., STEEL, K., TOPINKOVA, E., HAWES, C., IKEGAMI, N., HENRARD, J. C. & JONNSON, P. V. 1997. Nursing homes in 10 nations: a comparison between countries and settings. *Age and Ageing,* 26 Suppl 2**,** 3-12.

ROBSON, C. & MCCARTAN, K. 2016a. The analysis and interpretation of qualitative data. *Real World Research.* 4th ed. West Sussex: John Wiley & Sons Ltd.

ROBSON, C. & MCCARTAN, K. 2016b. Flexible designs. *Real World Research.* West Sussex: John Wiley & Sons Ltd.

ROBSON, C. & MCCARTAN, K. 2016c. Interviews and focus groups. *Real World Research.* 4th ed. West Sussex: John Wiley & Sons Ltd.

ROGERS, M., BETHEL, A. & BODDY, K. 2017. Development and testing of a medline search filter for identifying patient and public involvement in health research. *Health Information and Libraries Journal,* 34**,** 125-133.

ROGERS, P. 2015. 1.1 Admissions and discharges: principles, processes and planning. *In:* MULLEY, G., BOWMAN, C., BOYD, M. & STOWE, S. (eds.) *The Care Home Handbook.* West Sussex: Wiley Blackwell.

ROMERO-ORTUNO, R., FORSYTH, D. R., WILSON, K. J., CAMERON, E., WALLIS, S., BIRAM, R. & KEEVIL, V. 2017. The Association of Geriatric Syndromes with Hospital Outcomes. *Journal of Hospital Medicine,* 12**,** 83-89.

ROMERO-ORTUNO, R., O'DWYER, C., BYRNE, D., O'RIORDAN, D. & SILKE, B. 2014. A Risk Index for Geriatric Acute Medical Admissions (RIGAMA). *Acute Medicine,* 13**,** 6-11.

RUBIN, E., BUEHLER, A. & HALPERN, S. 2016. States Worse Than Death Among Hospitalized Patients With Serious Illnesses. *JAMA Internal Medicine,* 176**,** 1557-1559.

RUNDEK, T., HARTMANN, A., MAST, H., CHEN, X., GAN, R., DEMARIN, V. & SACCO, R. 1998. Stroke subtype as a predictor of nursing home placement: Northern Manhattan Stroke Study. *Acta Clinical Croatica,* 37**,** 175-180.

RUSS, T., BATTY, G. & STARR, J. 2012. Cognitive and behavioural predictors of survival in Alzheimer disease: results from a sample of treated patients in a tertiary-referral memory clinic. *International Journal of Geriatric Psychiatry,* 27**,** 844-853.

RUSS, T. C., STAMATAKIS, E., HAMER, M., STARR, J. M., KIVIMAKI, M. & BATTY, G. D. 2013. Socioeconomic status as a risk factor for dementia death: individual participant meta-analysis of 86 508 men and women from the UK. *British Journal of Psychiatry,* 203**,** 10-7.

RUSS, T. C., THOMSON, A. & LYONS, D. 2016. Medical certification of incapacity in guardianship applications: conceptualising capacity. *British Journal of Psychiatry Bulletin,* 40**,** 41-44.

SACKS, G. D., HILL, C. & ROGERS, S. O., JR. 2011. Insurance status and hospital discharge disposition after trauma: inequities in access to postacute care. *The Journal of Trauma,* 71**,** 1011-5.

SANDERSON, S., TATT, I. & HIGGINS, J. 2007. Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: a systematic review and annotated bibliography. *International Journal of Epidemiology,* 36**,** 666-676.

SANFORD, A. M., ORRELL, M., TOLSON, D., ABBATECOLA, A. M., ARAI, H., BAUER, J. M., CRUZ-JENTOFT, A. J., DONG, B., GA, H., GOEL, A., HAJJAR, R., HOLMEROVA, I., KATZ, P. R., KOOPMANS, R. T., ROLLAND, Y., VISVANATHAN, R., WOO, J., MORLEY, J. E. & VELLAS, B. 2015. An international definition for "nursing home". *Journal of the American Medical Directors Association,* 16**,** 181-4.

SCHLEGEL, D., KOLB, S. J., LUCIANO, J. M., TOVAR, J. M., CUCCHIARA, B. L., LIEBESKIND, D. S. & KASNER, S. E. 2003. Utility of the NIH Stroke Scale as a predictor of hospital disposition. *Stroke,* 34**,** 134-7.

SCHMUCKER, C. M., BLÜMLE, A., SCHELL, L. K., SCHWARZER, G., OELLER, P., CABRERA, L., VON ELM, E., BRIEL, M., MEERPOHL, J. J. & ON BEHALF OF THE OPEN CONSORTIUM. 2017. Systematic review finds that study data not published in full text articles have unclear impact on meta-analyses results in medical research. *PLoS ONE,* 12**,** e0176210.

SCHUNEMANN, H. J., OXMAN, A. D., VIST, G. E., HIGGINS, J., DEEKS, J. J., GLASZIOU, P., GUYATT, G. & ON BEHALF OF THE COCHRANE APPLICABILITY AND RECOMMENDATIONS METHODS GROUP 2011. Chapter 12: Interpreting results and drawing conclusions. In: Higgins JPT, Green S (editors), Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 (updated March 2011). The Cochrane Collaboration. Available: http://handbook.cochrane.org [Accessed 8th March 2017].

SCOTTISH GOVERNMENT. 2008. Adults with Incapacity (Scotland) Act 2000: A short guide to the Act. Available: http://www.gov.scot/Resource/Doc/217194/0058194.pdf [Accessed 4th December 2016].

SCOTTISH GOVERNMENT. 2009. *Adults with Incapacity (Scotland) Act 2000 Certificate of Incapacity under Section 47 of the Adults with Incapacity (Scotland) Act 2000* [Online]. Available: http://www.gov.scot/Resource/Doc/254430/0086221.pdf [Accessed 3rd January 2017].

SCOTTISH GOVERNMENT. 2011. Achieving Sustainable Quality in Scotland's Healthcare A '20:20' Vision. Available: http://www.gov.scot/Topics/Health/Policy/2020-Vision/Strategic-Narrative [Accessed 3rd October 2017].

SCOTTISH GOVERNMENT. 2012. Joined-up data for better decisions. Guiding Principles for Data Linkage. Available: http://www.gov.scot/Resource/0040/00407739.pdf [Accessed 14th April 2017].

SCOTTISH GOVERNMENT. 2013. Guardianship and Intervention Orders - making an application. Available: http://www.gov.scot/Resource/0044/00441134.pdf [Accessed 3rd January 2017].

SCOTTISH GOVERNMENT. 2015a. *Free Personal & Nursing Care* [Online]. Available: http://www.gov.scot/Topics/Health/Support-Social-Care/Support/Older-People/Free-Personal-Nursing-Care [Accessed 29th September 2015].

SCOTTISH GOVERNMENT. 2015b. *Guidance for 2015 Scottish Care Homes Census* [Online]. Available: http://www.gov.scot/Topics/Statistics/Browse/Health/ScottishCareHomeCensusB/GuidSCHC15 [Accessed 20th July 2016].

SCOTTISH GOVERNMENT. 2015c. Health and Social Care Integration. Public Bodies (Joint Working) (Scotland) Act 2014. Core Suite of Integration Indicators. Available: http://www.gov.scot/Topics/Health/Policy/Adult-Health-SocialCare-Integration/Outcomes/Indicators/Indicators [Accessed 25th November 2015].

SCOTTISH GOVERNMENT. 2015d. Hospital Based Complex Clinical Care. Available: http://www.sehd.scot.nhs.uk/dl/DL(2015)11.pdf [Accessed 30th December 2017].

SCOTTISH GOVERNMENT. 2016a. *Free Personal and Nursing Care, Scotland, 2014-15: 3. Expenditure* [Online]. Available: http://www.gov.scot/Publications/2016/04/1769/4 [Accessed 21st December 2017].

SCOTTISH GOVERNMENT. 2016b. Free Personal and Nursing Care, Scotland, 2015-16. Available: http://www.gov.scot/Resource/0052/00523923.pdf [Accessed 3rd November 2017].

SCOTTISH GOVERNMENT. 2016c. Health and Social Care Delivery Plan. Available: http://www.gov.scot/Resource/0051/00511950.pdf [Accessed 20th December 2016].

SCOTTISH GOVERNMENT. 2016d. *Integration of Health and Social Care, Scotland 2016.* [Online]. Available: http://www.gov.scot/Topics/Health/Policy/Adult-Health-SocialCare-Integration [Accessed 5th July 2016].

SCOTTISH GOVERNMENT. 2016e. *Scottish Government Funded Linkage Projects* [Online]. Available: http://www.gov.scot/Topics/Statistics/datalinkageframework/Funded-Linkage-Projects [Accessed 23rd October 2017].

SCOTTISH GOVERNMENT. 2017a. *Health & Social Care Integration* [Online]. Available: http://www.gov.scot/Topics/Health/Policy/Health-Social-Care-Integration [Accessed 7th October 2017].

SCOTTISH GOVERNMENT. 2017b. Inpatient Census, 2017: Hospital Based Complex Clinical Care & Long Stay. Available: http://www.gov.scot/Resource/0052/00526363.pdf [Accessed 30th December 2017].

SCOTTISH GOVERNMENT. 2017c. Social Care Services, Scotland, 2016. Available: http://www.gov.scot/Resource/0051/00510699.pdf [Accessed 10th November 2017].

SCOTTISH INTERCOLLEGIATE GUIDELINES NETWORK & HEALTH IMPROVEMENT SCOTLAND. 2017. *Search filters* [Online]. Available: http://www.sign.ac.uk/search-filters.html [Accessed 12th September 2017].

SCOTTISH LONGITUDINAL STUDY DEVELOPMENT & SUPPORT UNIT. 2017. *Scottish Longitudinal Study Development and Support Unit (SLS-DSU)* [Online]. Available: http://sls.lscs.ac.uk/ [Accessed 29th May 2017].

SCOTTISH PARLIAMENT 2000. Adults with Incapacity (Scotland) Act.

SCOTTISH PUBLIC SERVICE OMBUDSMAN. 2013. Case 201204498: Highland NHS Board. Available: http://www.spso.org.uk/sites/spso/files/investigation_reports/2013.08.21%20201204498%20Highland%20NHS%20Board.pdf [Accessed 7th November 2016].

SHARIFF, S. Z., SONTROP, J. M., HAYNES, R. B., IANSAVICHUS, A. V., MCKIBBON, K. A., WILCZYNSKI, N. L., WEIR, M. A., SPEECHLEY, M. R., THIND, A. & GARG, A. X. 2012. Impact of PubMed search filters on the retrieval of evidence by physicians. *Canadian Medical Association Journal,* 184**,** E184-90.

SHENKIN, S. D., HARRISON, J. K., WILKINSON, T., DODDS, R. M. & IOANNIDIS, J. P. A. 2017. Systematic reviews: guidance relevant for studies of older people. *Age and Ageing,* 46**,** 722-728.

SHERLAW-JOHNSON, C., SMITH, P. & BARDSLEY, M. 2016. Continuous monitoring of emergency admissions of older care home residents to hospital. *Age and Ageing,* 45**,** 71-7.

SINCLAIR, A. & DICKINSON, E. 1988. Effective Practice in Rehabilitation: The Evidence of Systematic Reviews. Available: http://archive.kingsfund.org.uk/18998/ [Accessed 14th November 2017].

SINCLAIR, S. & ROCKWELL, G. 2017. *Voyant Tools* [Online]. Available: https://voyant-tools.org/ [Accessed 3rd February 2017].

SLADEK, R., TIEMAN, J., FAZEKAS, B. S., ABERNETHY, A. P. & CURROW, D. C. 2006. Development of a subject search filter to find information relevant to palliative care in the general medical literature. *Journal of the Medical Library Association,* 94**,** 394-401.

SLADEK, R. M., TIEMAN, J. & CURROW, D. C. 2007. Improving search filter development: a study of palliative care literature. *BMC Medical Informatics and Decision-Making,* 7**,** 18.

SMITH, E. & STEVENS, A. 2009. Predictors of Discharges to a Nursing Home in a Hospital-Based Cohort. *Journal of the American Medical Directors Association,* 10**,** 623-629.

SOCIAL CARE INSTITUTE FOR EXCELLENCE. 2012. *At a glance 54: Reablement: a guide for familes and carers* [Online]. Available: https://www.scie.org.uk/publications/ataglance/ataglance54.asp [Accessed 12th November 2017].

SOOD, M. M., RIGATTO, C., BUETI, J., JASSAL, V., MILLER, L., VERRELLI, M., BOHM, C., MOJICA, J., ROBERTS, D. & KOMENDA, P. 2011. The role of functional status in discharge to assisted care facilities and in-hospital death among dialysis patients. *American Journal of Kidney Diseases,* 58**,** 804-12.

STANG, A. 2010. Critical evaluation of the Newcastle-Ottawa scale for the assessment of the quality of nonrandomized studies in meta-analyses. *European Journal of Epidemiology,* 25**,** 603-5.

STERNE, J., EGGER, M. & MOHER, D. E. 2011. Chapter 10: Addressing reporting biases. *In:* HIGGINS, J. & GREEN, S. (eds.) *Cochrane Handbook for Systematic Reviews of Intervention. Version 5.1.0 (updated March 2011). .* The Cochrane Collaboration. Available: http://handbook-5-1.cochrane.org/chapter_10/10_addressing_reporting_biases.htm [Accessed 27th January 2017].

STERNE, J. A., HERNAN, M. A., REEVES, B. C., SAVOVIC, J., BERKMAN, N. D., VISWANATHAN, M., HENRY, D., ALTMAN, D. G., ANSARI, M. T., BOUTRON, I., CARPENTER, J. R., CHAN, A. W., CHURCHILL, R., DEEKS, J. J., HROBJARTSSON, A., KIRKHAM, J., JUNI, P., LOKE, Y. K., PIGOTT, T. D., RAMSAY, C. R., REGIDOR, D., ROTHSTEIN, H. R., SANDHU, L., SANTAGUIDA, P. L., SCHUNEMANN, H. J., SHEA, B., SHRIER, I., TUGWELL, P., TURNER, L., VALENTINE, J. C., WADDINGTON, H., WATERS, E., WELLS, G. A., WHITING, P. F. & HIGGINS, J. P. 2016. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. *BMJ,* 355**,** i4919.

STEVENS, A., RAPHAEL, H. & GREEN, S. 2015. A qualitative study of older people with minimal care needs experiences of their admission to a nursing home with Registered Nurse care. *Quality in Ageing and Older Adults,* 16**,** 94-105.

STEWART, A. 2012. From family to personal responsibility: the challenges for care of the elderly in England. *Journal of Social Welfare and Family Law,* 34**,** 179-196.

STOSZ, L. & CARPENTER, I. 2008. Developing the use of MDS/RAI reports for UK care homes. Available: https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/2308-care-assessment-standards.pdf [Accessed 31st October 2017].

STOTT, D. J. & QUINN, T. J. 2017. Principles of rehabilitation of older people. *Medicine,* 45**,** 1-5.

SUDLOW, C., GALLACHER, J., ALLEN, N., BERAL, V., BURTON, P., DANESH, J., DOWNEY, P., ELLIOTT, P., GREEN, J., LANDRAY, M., LIU, B., MATTHEWS, P., ONG, G., PELL, J., SILMAN, A., YOUNG, A., SPROSEN, T., PEAKMAN, T. & COLLINS, R. 2015. UK Biobank: An Open Access Resource for Identifying the Causes of a Wide Range of Complex Diseases of Middle and Old Age. *PLOS Medicine,* 12**,** e1001779.

SURVEY MONKEY. 2017. *Welcome to Survey Monkey!* [Online]. Available: https://www.surveymonkey.co.uk/ [Accessed 14th February 2017].

SUTARIA, S., RODERICK, P. & POLLOCK, A. M. 2017. Are radical changes to health and social care paving the way for fewer services and new user charges? *BMJ* 358**,** j4279.

SWINKELS, A. & MITCHELL, T. 2008. Delayed transfer from hospital to community settings: the older person's perspective. *Health and Social Care in the Community,* 17**,** 45-53.

TAMLER, M. S. & PERRIN, J. C. 1992. Beaumont Lifestyle Inventory of Social Support. Can it predict disposition prior to an inpatient rehabilitation admission? *American Journal of Physical Medicine & Rehabilitation,* 71**,** 149-55.

TAYLOR, B. & DONNELLY, M. 2006. Professional Perspectives on Decision Making about the Long-term Care of Older People. *British Journal of Social Work,* 36**,** 807-26.

TAYLOR, J. S., DEMERS, S. M., VIG, E. K. & BORSON, S. 2012. The disappearing subject: exclusion of people with cognitive impairment and dementia from geriatrics research. *Journal of the American Geriatrics Society,* 60**,** 413-9.

TAYLOR, L. & LYNCH, E. 2010. Linking social care, housing & health data. Data Linkage Literature Review. Available: http://www.gov.scot/Resource/Doc/924/0119579.pdf [Accessed 14th December 2016].

TEALE, E. A., MUNYOMBWE, T., SCHUURMANS, M., SIDDIQI, N. & YOUNG, J. 2018. A prospective observational study to investigate utility of the Delirium Observational Screening Scale (DOSS) to detect delirium in care home residents. *Age and Ageing,* 47**,** 56-61.

TERWEE, C. B., JANSMA, E. P., RIPHAGEN, I. I. & DE VET, H. C. W. 2009. Development of a methodological PubMed search filter for finding studies on measurement properties of measurement instruments. *Quality of Life Research,* 18**,** 1115-1123.

THOMAS, D. R. 2006. A General Inductive Approach for Analzing Qualitative Evaluation Data. *American Journal of Evaluation,* 27**,** 237-246.

THOMAS, J., MCNAUGHT, J. & ANANIADOU, S. 2011. Applications of text mining within systematic reviews. *Research Synthesis Methods,* 2**,** 1-14.

TOLSON, D., ROLLAND, Y., KATZ, P., WOO, J., MORLEY, J. & VELLAS, B. 2013. An International Survey of Nursing Homes. *Journal of the American Medical Directors Association,* 14**,** 459-462.

TOMBAUGH, T. N. & MCINTYRE, N. J. 1992. The mini-mental state examination: a comprehensive review. *Journal of the American Geriatrics Society*, 40, 922-35.

TONG, A., SAINSBURY, P. & CRAIG, J. 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care,* 19**,** 349-357.

TOOT, S., SWINSON, T., DEVINE, M., CHALLIS, D. & ORRELL, M. 2017. Causes of nursing home placement for older people with dementia: a systematic review and meta-analysis. *International Psychogeriatrics,* 29**,** 195-208.

TORPILLIESI, T., BELLELLI, G. & TRABUCCHI, M. 2010. Delirium superimposed on dementia is more predictive of adverse outcomes than dementia alone. *International Journal of Geriatric Psychiatry,* 25**,** 433-436.

TREGER, I., RING, H., SCHWARTZ, R., TSABARI, R., BORNSTEIN, N. M. & TANNE, D. 2008. Hospital disposition after stroke in a national survey of acute cerebrovascular diseases in Israel. *Archives of Physical Medicine and Rehabilitation,* 89**,** 435-40.

TURCO, R., BELLELLI, G., MORANDI, A., GENTILE, S. & TRABUCCHI, M. 2013. The effect of poststroke delirium on short-term outcomes of elderly patients undergoing rehabilitation. *Journal of Geriatric Psychiatry and Neurology,* 26**,** 63-8.

TURNER, M., BARBER, M., DODDS, H., DENNIS, M., LANGHORNE, P. & MACLEOD, M. J. 2015. Agreement between routine electronic hospital discharge and Scottish Stroke Care Audit (SSCA) data in identifying stroke in the Scottish population. *BMC Health Services Research,* 15**,** 583.

UK DATA SERVICE. 2015. *Access to sensitive data for research: 'The 5 Safes'* [Online]. Available: http://blog.ukdataservice.ac.uk/access-to-sensitive-data-for-research-the-5-safes/ [Accessed 14th April 2017].

UNIVERSITY OF DUNDEE. 2017. *Health Informatics Centre - Trusted Research Environment* [Online]. Available: https://www.dundee.ac.uk/hic [Accessed 30th April 2017].

UTHAMALINGAM, S., GURM, G. S., DALEY, M., FLYNN, J. & CAPODILUPO, R. 2011. Usefulness of acute delirium as a predictor of adverse outcomes in patients >65 years of age with acute decompensated heart failure. *The American Journal of Cardiology,* 108**,** 402-8.

VALENTINE, J. C. & THOMPSON, S. G. 2013. Issues relating to confounding and meta-analysis when including non-randomized studies in systematic reviews on the effects of interventions. *Research Synthesis Methods,* 4**,** 26-35.

VAN DE GLIND, E. M., VAN MUNSTER, B. C., SPIJKER, R., SCHOLTEN, R. J. & HOOFT, L. 2012. Search filters to identify geriatric medicine in Medline. *Journal of the American Medical Informatics Association,* 19**,** 468-72.

VAN NES, M.-C., HERRMANN, F., GOLD, G., MICHEL, J.-P. & RIZZOLI, R. 2001. Does the Mini Nutritional Assessment predict hospitalization outcomes in older people? *Age and Ageing,* 30**,** 221-226.

VERBEEK, H., MEYER, G., CHALLIS, D., ZABALEGUI, A., SOTO, M. E., SAKS, K., LEINO-KILPI, H., KARLSSON, S., HAMERS, J. P. & RIGHTTIMEPLACECARE CONSORTIUM. 2015. Inter-country exploration of factors associated with admission to long-term institutional dementia care: evidence from the RightTimePlaceCare study. *Journal of Advanced Nursing,* 71**,** 1338-50.

VERBEEK, H., MEYER, G., LEINO-KILPI, H., ZABALEGUI, A., HALLBERG, I., SAKS, K., SOTO, M., CHALLIS, D., SAUERLAND, D. & HAMERS, J. P. H. 2012. A European study investigating patterns of transition from home care towards institutional dementia care: the protocol of a RightTimePlaceCare study. *BMC Public Health,* 12**,** 68.

VISWANATHAN, M. & BERKMAN, N. D. 2012. Development of the RTI item bank on risk of bias and precision of observational studies. *Journal of Clinical Epidemiology,* 65**,** 163-78.

VON ELM, E., ALTMAN, D., EGGER, M., POCOCK, S., GOTZSCHE, P., VANDENBROUCKE, J. & FOR THE STROBE INITIATIVE 2008. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *Journal of Clinical Epidemiology,* 61**,** 344-349.

WARREN, M. W. 1943. Care of Chronic Sick. *BMJ,* 2**,** 822-3.

WARREN, M. W. 1946. Care of the chronic aged sick. *The Lancet,* 1**,** 841-3.

WATKIN, L., BLANCHARD, M. R., TOOKMAN, A. & SAMPSON, E. L. 2012. Prospective cohort study of adverse events in older people admitted to the acute general hospital: risk factors and the impact of dementia. *International Journal of Geriatric Psychiatry,* 27**,** 76-82.

WELLS, G., SHEA, B., O'CONNELL, D., PETERSON, J., WELCH, V., LOSOS, M. & TUGWELL, P. 2014. *The Newcastle-Ottawa Scale (NOS) for assessing the quality if nonrandomised studies in meta-analyses* [Online]. Available: http://www.ohri.ca/programs/clinical_epidemiology/oxford.asp [Accessed 5th August 2015].

WELLS, G. A., SHEA, B., HIGGINS, J. P., STERNE, J., TUGWELL, P. & REEVES, B. C. 2013. Checklists of methodological issues for review authors to consider when including non-randomized studies in systematic reviews. *Research Synthesis Methods,* 4**,** 63-77.

WEST, E., STUCKELBERGER, A., PAUTEX, S., STAAKS, J. & GYSELS, M. 2017. Operationalising ethical challenges in dementia research-a systematic review of current evidence. *Age and Ageing,* 46**,** 678-687.

WILCZYNSKI, N. L., LOKKER, C., MCKIBBON, K. A., HOBSON, N. & HAYNES, R. B. 2016. Limits of search filter development. *Journal of the Medical Library Association,* 104**,** 42-6.

WILLIAMSON, P. R., ALTMAN, D. G., BLAZEBY, J. M., CLARKE, M., DEVANE, D., GARGON, E. & TUGWELL, P. 2012. Developing core outcome sets for clinical trials: issues to consider. *Trials,* 13**,** 132.

WILSON, S. A. 1997. The transition to nursing home life: a comparison of planned and unplanned admissions. *Journal of Advanced Nursing,* 26**,** 864-71.

WITHAM, M. D., FROST, H., MCMURDO, M., DONNAN, P. T. & MCGILCHRIST, M. 2015. Construction of a linked health and social care database resource--lessons on process, content and culture. *Informatics for Health & Social Care,* 40**,** 229-39.

WITLOX, J., EURELINGS, L. S., DE JONGHE, J. F., KALISVAART, K. J., EIKELENBOOM, P. & VAN GOOL, W. A. 2010. Delirium in elderly patients and the risk of postdischarge mortality, institutionalization, and dementia: a meta-analysis. *JAMA: The Journal of the American Medical Association,* 304**,** 443-51.

WITTENBERG, R., SHARPIN, L., MCCORMICK, L. & HURST, J. 2015. Understanding emergency hospital admission of older people. Available: http://eprints.lse.ac.uk/60622/ [Accessed 12th November 2017].

WOMERSLEY, J. 1996. The public health uses of the Scottish Community Health Index (CHI). *Journal of Public Health Medicine,* 18**,** 465-72.

WONG, A., ELDERKAMP-DE GROOT, R., POLDER, J. & VAN EXEL, J. 2010. Predictors of Long-Term Care Utilization by Dutch Hospital Patients aged 65+. *BMC Health Services Research,* 10**,** 110.

WONG, G., WESTHORP, G., MANZANO, A., GREENHALGH, J., JAGOSH, J. & GREENHALGH, T. 2016. RAMESES II reporting standards for realist evaluations. *BMC Medicine,* 14**,** 96.

WOOD, R. C., D, KING, A., MACKAY, D. & PELL, J. 2013. Novel cross-sectoral linkage of routine health and education data at an all-Scotland level: a feasibility study. *The Lancet,* 382**,** S10.

WORLD HEALTH ORGANIZATION. 2017. *10 Priorities for a Decade of Action on Healthy Ageing* [Online]. Available: http://www.who.int/ageing/10-priorities/en/ [Accessed 26th November 2017].

WUBKER, A., ZWAKHALEN, S. M., CHALLIS, D., SUHONEN, R., KARLSSON, S., ZABALEGUI, A., SOTO, M., SAKS, K. & SAUERLAND, D. 2015. Costs of care for people with dementia just before and after nursing home placement: primary data from eight European countries. *European Journal of Health Economics,* 16**,** 689-707.

XAFIS, V. 2015. The acceptability of conducting data linkage research without obtaining consent: lay people's views and justifications. *BMC Medical Ethics,* 16**,** 79.

YANCEY, W. 2007. *BigMatch: A Program for Extracting Probable Matches from a Large File* [Online]. Washington D,C,: Statistical Research Division U.S. Bureau of the Census,. Available: https://www.census.gov/srd/papers/pdf/rrc2007-01.pdf [Accessed 15th December 2017].

YIN, R. K. 2009. *Case Study Research Design and Methods,* California, Sage.

ZARIT, S. H. & WHITLATCH, C. J. 1992. Institutional placement: phases of the transition. *The Gerontologist,* 32**,** 665-72.

ZEKRY, D., HERRMANN, F., GRANDJEAN, R., VITALE, A.-M., DE PINHO, M.-F., MICHEL, J.-P., GOLD, G. & KRAUSE, K.-H. 2009. Does dementia predict adverse hospitalization outcomes? A prospective study in aged inpatients. *International Journal of Geriatric Psychiatry,* 24**,** 283-291.

ZISBERG, A., SINOFF, G., AGMON, M., TONKIKH, O., GUR-YAISH, N. & SHADMI, E. 2016. Even a small change can make a big difference: the case of in-hospital cognitive decline and new IADL dependency. *Age and Ageing,* 45**,** 500-4.

ZUREIK, M., LANG, T., TROUILET, J.-L., DAVIDO, A., TRAN, B., LEVY, A. & LOMBRAIL, P. 1995. Returning Home after Acute Hospitalization in Two French Teaching Hospitals: Predictive Value of Patients' and Relatives' Wishes. *Age and Ageing,* 24**,** 227-234.